

ANGLIA RUSKIN UNIVERSITY

**A GROUNDED CONSTRUCTION OF SHARED DECISION
MAKING FOR PSYCHIATRIC MEDICATION MANAGEMENT:
FINDINGS FROM A COMMUNITY MENTAL HEALTH TEAM**

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A thesis in partial fulfilment of the requirements of Anglia
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ANGLIA RUSKIN UNIVERSITY
ABSTRACT
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Decisions concerning psychiatric medication are complex and often involve a protracted process of trial and error. The serious and enduring nature of side effects associated with psychiatric medication demands that medical and experiential expertise is shared in a way that is supportive of the longer term recovery journey. Historically poor concordance rates point to a lack of trust and difficulties in sharing decisions constructively. This Ph.D explores views and experiences of shared decision making for psychiatric medication management amongst mental health service users and practitioners.

The study was conducted in a community mental health service, in the UK. A participatory methodology was employed, within a social constructionist paradigm. Service users and a carer were involved in all phases of the research process. Thirty qualitative interviews were undertaken with different stakeholders: psychiatrists, community psychiatric nurses, and service users. A thematic analysis was employed. In addition, an applied conversation analysis was undertaken on four recorded outpatient medication related meetings.

Enablers of and barriers to shared decision making were found at three levels of analysis: the interaction, the relationship, and the system. Many divergent discourses were apparent across these levels, both within and between the different stakeholder groups. A typology of involvement is proposed and discussed, from *fractured passivity* through to *active self- management*. The barriers to collaborative practice identified in these findings, and the structural factors at work in the mental health system in particular, were seen to explain the gap between policy ideals and current practice. Strong therapeutic relationships were found to be a vital enabler, comprising of: a formation of trust, practitioners knowing and believing in service users' potential, and 'walking the journey together'.

Shared decision making in this study is found to be a dynamic process over time, involving two (or more) participants in a complex interplay. The thesis emphasizes the interaction between structure and agency in shared decision making in psychiatric medication management and highlights how power is enacted in the context of shared decisions in a community setting.

Original theoretical, methodological and practical contributions to knowledge are presented and discussed.

Key words: shared decision making, psychiatric medication management, recovery, mental health, participatory methodology

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"He who does not know one thing knows another."

Kenyan Proverb

"We don't accomplish anything in this world alone... and whatever happens is the result of the whole tapestry of one's life and all the weavings of individual threads form one to another that creates something".

Sandra Day O'Connor, Supreme Court Justice

"Knowledge, if it does not determine action, is dead to us. Knowledge has three degrees-opinion, science, illumination. The means or instrument of the first is sense; of the second, dialectic; of the third, intuition".

Plotinus 204 or 205 C.E., Egyptian Philosopher

Introduction

In this section, I briefly describe the context and rationale for the research in relation to current policy and practice in psychiatric medication management. I will then present the wider community roots that have shaped the scope, aims and ethos of this study, reflecting on my own position and outsider status at the onset of the study. The introduction concludes with an overview of the layout of the thesis and chapter content.

0.1. Empirical rationale and brief description of the study

This thesis explores the views and experiences of both service users and practitioners, building a comprehensive understanding of the everyday realities of shared decision making for psychiatric medication management, in a community based mental health team.

Psychotropic medication is the key component of many mental health treatment plans (Healy, 2009). Medication can be an important tool for an individual's personal recovery, but decisions pertaining to medication are complex and involve a process of trial and error, where potential benefits are weighed up against the adverse impacts medication may have for a person's functioning, quality of life and identity (Deegan, 2005;2007; Kartalova-O'Doherty and Tedstone-Doherty, 2010). Service users may grow in expertise and refine medication strategies over time finding the *right balance between what they do to be well and what they take to be well* (MacDonald -Wilson et al, 2013, p. 263). However, often people who are prescribed psychiatric medication do not take it systematically and do not share this information with their doctor. Strategies such as only taking medication at certain times or non adherence may, for some, act as a positive attempt at self management (Britten et al, 2010; Pound et al, 2005; Roe et al, 2009). Yet previous research suggests that often service users do not inform or consult practitioners in the serious decision to come off psychiatric medication (Read, 2005). This highlights lack of trust between mental health service users and their clinicians, and difficulties in sharing knowledge, both scientific and experiential.

It is proposed that shared decision making offers opportunities for service user knowledge and experience of taking and using psychiatric medication to move to the fore, thereby enabling greater empowerment, enhanced control, and a partnership with practitioners in their personalised treatment plan (Deegan and Drake, 2006; Drake, Deegan and Rapp, 2010; Baker et al, 2013). Here the service provider and prescribers' role is to assist in the

process of individual led recovery, with a corresponding move away from clinically defined care (Shepherd, Boardman and Slade, 2008).

The model of shared decision making has been growing in support and is now ingrained into policy and professional discourse, sitting within the larger move towards recovery based practice in mental health. This, along with person centred care is now considered to be a core component of the UK mental health system (NIMHE, 2005; DH, 2009;2012a;2011a).

However, transactional models of SDM and research exploring its utility have originated in other fields of medicine. Far less research has been undertaken in mental health that explores service user involvement in decision making concerning psychiatric medication. This PhD thesis adds to existing knowledge by exploring both service users' and practitioners' views and experiences of shared decision making for psychiatric medication management, allowing for a contextualised and grounded conceptualisation to emerge.

0.2. Local historical context

The roots of this research lie in the wider local community within which the research has taken place. Following MIND's well publicised report which looked into the experiences of people trying to come off psychiatric drugs (Read, 2005), a group of passionate and concerned people came together locally, to discuss their own experiences and views about psychiatric medication management practice. This group consisted of mental health service users, mental health service providers, carers, and researchers¹. The group met on a regular basis and grew in membership and recognition. Demand was such that in 2007 a conference was organised locally, attended by over 100 delegates. While discussion and debate remained the focus, tangible outputs from this event centred on the need to build more understanding about people's experiences and views of sharing decisions about psychiatric medication, with the aim of promoting increased awareness, reflection and change. This PhD was originally conceived as supporting the action research project on shared decision making in psychiatric medication (later funded by the RfPB scheme of the NIHR² in 2011). Thus, this study has been subsequently shaped by and I hope ultimately contributes to this wider community initiative, to bring about positive change in people's day to day experiences of medication management practice.

¹ Professor Shulamit Ramon, PhD supervisor, was a member of this group

² Research for Patient Benefit program, National Institute for Health Research

I first met the supervisory team for this project as part of a panel interview for the PhD studentship in December 2009. I was excited at the prospect of being involved, yet conscious of my own naivety and lack of personal experiential understanding about mental ill health or indeed mental health services. I was also aware that I did not have a particular psychiatric or nursing background, or in participatory research, which hindered my confidence. However I felt my 'outsider' status would be helpful in remaining focused on emergent findings, as opposed to a priori knowledge, and be sensitive and grounded to the life world of the participants as oppose to being heavily influenced by a set of pre existing conceptions. Since the onset of the research, the focus has remained on acknowledging differing perspectives and experiences and embracing complexity. Power was an important theme throughout, in both the undertaking of the research, and for the conceptual framework of the study. I reflected on power differentials between; myself as academic researcher and both service user participants and co researchers; and also in the dynamics between the advisory group members. My academic training in research methodology (for Psychology) prior to the PhD provided me with some comfort in the early phases of the research planning process, but subsequently much of my academic objectivism was challenged as I embraced the values and participatory ethos of the study. This remains for me the most important aspect of this project personally and the knowledge that research is, in of itself, a way of engaging with the social nature of reality, and can promote change and reflection.

There were two overarching research questions for this thesis:

- What are key stakeholder views about shared decision making for psychiatric medication management?
- How are decisions about psychiatric medication made in practice?

Within these overarching research questions, some key research themes were identified:

- What are the enablers of and barriers to SDM for psychiatric medication management?
- Current medication management practice in a community-based mental health service
- Similarities and differences in how SDM is conceptualised between stakeholder groups
- Acknowledgement of a need for change, making recommendations for practice based on the findings.

A social constructionist paradigm and participatory ethos underpinned the research. Co researchers' contributions throughout the study are reflected in the written thesis presented. The study describes how different stakeholder groups viewed meaningful involvement and builds on key stakeholders' valuable experience and in depth

understanding of sharing decisions in practice. There were two phases to the data collection process: an in depth research interview and recorded meetings. Findings emerged at three levels of analysis (the interaction; the relationship; the system) and these support a broader conceptualisation of SDM. Theoretical and practical implications are discussed and methodological contributions are considered.

0.3 The thesis layout and chapter outline

Not including this introductory section, the thesis consists of 10 chapters.

Chapter One describes the context of the study. The contemporary historical and policy context for mental health services in the UK is introduced. The role of psychiatric medication in community based mental health services is critiqued, alongside a presentation of key trends and changes in the provision of mental health services. The model of personal recovery is highlighted as a key policy for shared decision making in psychiatric medication management practice. The concept of personal recovery, its historical roots and influence on contemporary mental health service delivery, are considered.

Chapter Two - the literature review - begins with an overview of dominant models of decision making in healthcare. This is followed by a discussion and critique of the model of shared decision making and an examination of broader constructs of collaboration and involvement. The second part of this chapter explores the research that has examined decision making preferences and practice in mental health. This section explores how applicable are models, such as shared decision making, to making decisions about psychiatric medication. Barriers to achieving meaningful involvement in mental health are also considered. Gaps in the current literature are highlighted, and the research questions are described, highlighting the study's original contribution to knowledge.

In Chapter Three, the theoretical construct of power is considered and influential theories are evaluated, focussing on their applicability to the context of psychiatric medication management. The chapter concludes with a presentation of the conceptual framework for the thesis.

Chapter Four considers the philosophical assumptions, values, methodological choices and research design of the study. Tensions that arise, as well the potentially illuminating aspects of the chosen methodology, are highlighted. I draw particular attention to the

participatory ethos of the research, exploring how this enhances the knowledge produced. Key decisions made in the data collection methods and analytical approaches are described, alongside consideration of ethical issues and strategies for validating findings.

Chapters Five, Six, and Seven present findings from the research interviews conducted with service users; community psychiatric nurses; and psychiatrists respectively. Findings are presented at three levels analysis: the interaction, the relationship and the system. A summary of the commonalities and areas of differences both within and between the stakeholder groups are provided.

Chapter Eight presents findings from phase two of the data collection process: the recorded meetings. This chapter supplements themes presented in Chapters Five, Six, and Seven and contributes additional understanding of how decision making is being shared in the encounters. Relevant interview data from phase one, additional contextual information, and the dynamics of the recorded meetings are incorporated within the presentation of findings. Links to phase one findings are discussed and the diversity between meetings explored.

Chapter Nine draws together the findings presented in Chapters Five through to Eight, linking findings to the existing literature, models of shared decision making, and the theoretical construct of power. A broader conceptualisation of shared decision making for psychiatric medication management is supported, emphasising the dynamic and protracted nature of the process. Three levels of analysis: the interaction, the relationship, and the system, are used to structure the discussion. Divergent discourses are discussed at each level of analysis. At the interaction level, a typology of involvement is offered, comprising: Fractured passivity; Tactful manipulation; Shared; and Active Self-Management.

Chapter Ten concludes the thesis with a discussion of the implications of the findings for mental health policy and practice. Theoretical and methodological contributions to knowledge are presented. I consider the limitations of the study and make recommendations for further research.

Chapter One. The research context.

Chapter outline

This chapter highlights the timeliness and relevance of the study by exploring the contemporary historical and policy context for psychiatric medication management practice. The role of psychiatric medication in community based mental health services is highlighted, alongside a presentation of key trends and changes in the provision of mental health services. The model of personal recovery is described and evaluated as a key policy for shared decision making in psychiatric medication management practice.

1.1 Contemporary UK mental health service provision.

1.1.1. Historical and Policy context since the 1980s.

How mental health services are delivered today is fundamentally different to that of a few decades ago. Today, one of the cornerstones of modern psychiatric practice is the 'multi-disciplinary team', with social workers, occupational therapists, counsellors, clinical psychologists, and community psychiatric nurses, among others working as generic mental health professionals in the delivery of care. The professionalisation of different practitioner groups in community based mental health teams has been an important trend during this time frame (Shorter, 2006). Whether this has led to fundamental impact on the cultural practice of mental health delivery service, nonetheless, remains questionable³. Regardless, the community mental health approach is associated with a number of improvements in service delivery (Thornicroft and Tansella, 2004). Under the labour government, mental health services saw the introduction of the National Service Framework(NSF) (DH, 1999) and a more functionalised approach, moving away from generic community mental health teams⁴ (Glasby, 2012).

But, more broadly, since the 1980s there has been transformational change, away from psychiatric hospitals and institutional based care, towards care in the community. The use of psychiatric medication for therapeutic purposes has also been increasing over this period. For example, the percentage of depressed outpatients treated with

⁴ With for example the introduction of *assertive outreach teams and early intervention services*.

psychopharmacology has risen from 44.6 % in 1987 to 79.4% in 1997 (Olfson et al, 2002). To what extent the growth in psychopharmacology has driven closure of psychiatric hospitals is contested (see Ramon, 1992; Pilgrim et al, 2011 for fuller discussion). Nevertheless, it has been suggested that psychopharmacology has encouraged health care reforms. For example, advent of the depot antipsychotic in the 1960s enabled increased compliance and consequently enabled greater community care (Shorter, 2006).

Alongside the move away from institutionalised care there has also been a broader shift in how need is conceptualised, with increased emphasis on human rights and social inclusion over this time frame. The social model of disability has had a significant impact on culture and societal attitudes towards social inclusion, representing a cornerstone for user movements in this time period. In short, the social model of disability has changed the focus from impairments of the individual and policy emphasis on charity and medical care, to an appreciation of society's failure to accommodate diverse needs and policies focussed on rights, equality and citizenship.

Associated shifts and, in particular, the mental health 'survivor' movement⁵ have meant that psychological and social interventions have gained momentum alongside increased attempts at social change and stigma reduction⁶. Stigma is now well reported as a huge challenge for people with mental health problems leading to discrimination, social marginalisation and isolation. As Secker (2011) comments *the existence of the stigma creates a climate in which the abilities to contribute to society of this group of people are largely ignored, as highlighted, for example, by high unemployment* (ibid, p. 497). Significant investment from the Department of Health (DH) in 2009's Time to Change campaign indicates that stigma reduction is a key priority in UK policy. Initial evaluation is promising and positive impact of the campaign on public attitudes and stigma is emerging (Hendenson and Thornicroft, 2009; 2013). However, recent changes to unemployment and disability benefits under the coalition government could have a further negative impact in this regard (Glasby, 2012).

The promotion of social inclusion also links to an increased emphasis on empowerment (Secker, 2011). Initiatives such as support for the use of advance directives (where a person specifies their treatment preferences in case they become unwell) have emerged in recent years, promoting the broader agenda of personalisation. However, this is not to

⁶ Also see S. 2.2

suggest that such initiatives in mental healthcare are widespread or ingrained into modern mental health care culture. In fact, the uptake of initiatives such as advance directive planning is surprisingly low, with collective resistance from practitioner bodies reported (Morris - Thompson et al, 2013).

Related to this, neoliberal ideals of individualisation, increased choice and marketisation are increasing in their prominence in mental health policy in the UK (Ramon, 2008). The dominant rhetoric of choice and patient centred care, alongside the ratification of the Health and Social Care Act 2012, is an important contextual feature of contemporary mental health services. How these changes will impact on the experience of choice by service users, nevertheless remains uncertain and under investigated (Naylor, 2012). Mental health policy has received increased attention within the broader policy reforms underway in health and social care. Wellbeing and mental health are at the top of the list of public health priorities in the newly organised health and wellbeing directorate of Public Health England (PHE, 2013). This is reinforced by recent policy that has placed increased priority on creating parity between mental and physical health (DH, 2011a).

While the impact of the wider reforms on mental health services remain uncertain the trend in the delivery of services towards continued and increased emphasis on the marketisation and the liberalisation of financial arrangements in the NHS is apparent. The current coalition government are focussing priorities towards a greater access to information, including for example greater use of 'patient reported outcome measures'. A key strategy is to create greater choice of providers, with new organisations overseeing the local accountability of services. Commissioners are starting to pay for services, using mental health care clusters to operationalise the process. But many unanswered questions remain and implementation is still in its infancy⁷.

The term shared decision making is ingrained within the policy rhetoric, following the white paper *Choice and Equity* and subsequent consultation document '*Liberating the NHS: No decision about me, without me*' (DH, 2010;2012a). In response to this consultation, there has been growing concern that too much emphasis has been placed on provider choice and too little emphasis has been placed on the dialogue between service user and clinician (Coulter and Collins, 2011; RC Psych, 2012). According to the Royal College of Psychiatrist's response to the DH (2012) consultation:

⁷ A care cluster identifies the needs of the service user, takes into account diagnosis and makes recommendations for care

Service users place the highest value on quality of service, rather than on choice of service. Research in psychotherapy consistently shows that allowing people to choose the type of therapy they want is positively related to outcome. However, we are not aware of any similar evidence around the choice of provider. The document [DH,2012] concentrates too much on the choice of provider and pays very little attention to the vital dialogue between clinician and patient.

(ibid, pp. 5 - 6)

Although it is proposed that broadening the range of choice is still less well developed in mental health than other health policy contexts (Beresford, 2002; Beresford and Carr, 2012), it has nevertheless been argued that this shift has offered positive developments to mental health service delivery, alongside the emergence of contemporary challenges. For example, the increased provision of user led services is arguably a related outcome of such trends (Ramon, 2008). In addition, the associated trend of increased user involvement in the development of mental health policies, training and research, staff selection, advocacy, alongside the emergence of consumer directed services, such as personalised health budgets (DH, 2009;2012b), to allow people to choose and purchase some of the services they need, may increase service user control and change the way service users interact with services (RC Psych, 2013). However, paradoxically, recent reports have highlighted a continued increase in more coercive forms of practice (Health and Social Care Information Centre, 2012). For example, in the year 2012 – 2013 there was a 12% increase in detentions under the Mental Health Act (Care Quality Commission, 2014). Indeed, it has been suggested that the growth in neo liberalism has conversely resulted in a contradictory trend towards increased regulation and governmental control, preoccupation with risk avoidance and a reduction in the autonomy or competitiveness of the voluntary sector in service provision (Ramon, 2008). There are also well voiced concerns that features of broader health and social care policy towards personalisation and choice do not necessarily complement the focus on social inclusion mentioned above (Glasby, 2012; Secker, 2011; Coulter and Collins, 2012).

Finally, the wider tough economic climate is an important broader contextual feature within which contemporary mental health services operate, likely to impact on the implementation of the new forms of service delivery, mentioned above (Glasby, 2012). While the direct impact of the broader economic climate on mental health services is still uncertain, the trend towards cost cutting in health and social care and the widespread welfare reforms underway, alongside the growth in demand on services provides additional and significant strain on the system. For example a report recently released

found there was a relationship between welfare reforms in Scotland and increased demand on mental health services, via the routes of both increased stigmatisation associated with claiming benefits and increased anxieties associated with; high levels of unemployment; rising poverty; and increasing levels of job insecurity and part time working (McCartney et al, 2013).

The broad and complex contextual features of mental health service provision in the UK have been briefly presented. The next section will discuss the dominant models of classification and treatment for mental health services and critique the role psychotropic medication performs in contemporary services. This is followed by an examination of the recovery model as a key policy for contemporary mental health services more generally, and for shared decision making for psychiatric medication management more specifically.

1.2. Diagnosis and treatment

The current International Classification of Diseases (ICD 10) defines mental illness as: *the existence of a clinically recognisable set of symptoms or behaviours associated in most cases with distress and with interference with personal functions.*

Within mental health policy the bio psycho social model is dominant in the UK. While not always viewed as complementary, models such as the 'stress vulnerability model' (Zubin and Spring, 1977) have received widespread support, exploring factors which increase an individual's vulnerability as well as highlighting maintaining factors for mental ill health. Mental health treatments offered in the UK today, also fall under these three broad categories. That is biological treatments, including psychopharmacology, but also other physical treatments, such as Electroconvulsive therapy; Psychological treatments such as CBT and psychotherapy; and psychosocial interventions such as family interventions and case management (Knapp, McDaid et al, 2008). The IAPT program (Improving Access to Psychological Therapies) has improved provision of psychological therapies, mainly CBT, for people diagnosed with depression and anxiety disorders. A second phase was launched in 2011 to also include 'severe mental illness' (DH, 2011b).

Other recent therapies not usually available through the IAPT program, such as the Soteria therapeutic community approach (Mosher, 1999) and the 'open dialogue' approach have also been growing in support and evidence in recent years (Seikkula et al, 2011). For example, it has been found that with a minimal use of medication or no use at all, but within a context of an open dialogue between multidisciplinary professionals, service

users and family members, positive outcomes are observed (Seikkula et al, 2011). Social support networks and groups such as the hearing voices network, which emphasise sharing experiences of mental illness and establishing new meanings and developing alternative approaches of being in control, have also received growing interest in recent years (Romme, 2009).

Nevertheless it remains the case that biological therapies and in particular prescription of psychotropic medication remains the dominant approach. In fact most people who receive psychiatric services in the UK are prescribed one sort of psychiatric drug, and often several (Moncrieff, 2009; Healy, 2009). Conversely implementation of the 'non medical' therapies remains patchy and inconsistent. There appears a disconnection between what the 'lay person' expects from mental health services and the service provision available. For example, whilst psychotherapy and psychology is valued by most, there is little appreciation in the general public that psychiatrists are medical doctors by training, many without specific training in psychotherapy (Stevenson, 2000; Sartorius et al, 2010). Relations between mental health professionals and service users often revolve around medication (Moncrieff, 2009).

Trend data supports this in that during the 20 years from 1980 to 2000 there was about a 30% increase in prescriptions for the four main classes of drugs used for psychiatric conditions - hypnotics and anxiolytics, anti-psychotics, antidepressants. Expenditure on psychiatric drugs remained constant, at about 8% of NHS drug expenditure in 2000 (Rose, 2003). However, this Figure does not consider the differing trends for different classes of psychiatric drugs over this period. Certain medications, namely sleeping pills and minor tranquillisers, whose use received cause for concern, decreased over this period, whereas there was a large increase in other classes of psychiatric medication, for example, an incredible rise of 200% in anti-depressant prescription (Rose, 2003).

In summary, mental illness and its antecedents is a contested and multifaceted area, yet the dominant approach in services remains the prescription of psychotropic medication. Linked to this, psychiatric diagnosis also remains the cornerstone of how mental health services are delivered. However psychiatric diagnoses are not validated like other medical conditions and there is a long history of debate and controversy surrounding their use (Pilgrim, 2007). The fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, known as DSM - 5, was published on May 18th, 2013 in the face of widespread criticism. For example, the British Psychological Society's earlier consultation response stated that diagnoses were problematic and unhelpful:

[diagnoses] as clearly based largely on social norms, with symptoms that rely on subjective judgements, not value free, but rather reflecting current normative social expectation.... We believe that a description of a person's real problems would suffice. Moncrieff and others have shown that diagnostic labels are less useful than a description of a person's problems for predicting treatment response, so again diagnoses seem positively unhelpful compared to the alternatives

(British Psychological Society, 2011, p. 2)

However criticism also emerges from within the biological psychiatry perspective. For example, the National Institute of Mental Health (NIMH) criticises the approach in their blog, as lacking validity, making the analogy with other areas of medicine.

In the rest of medicine, this would be equivalent to creating diagnostic symptoms based on the nature of chest pain or the quality of fever....over the last half a century we have understood that symptoms alone rarely indicate the best choice of treatment.

(Insel, 2013)

In addition wide spread criticisms have been voiced on the concerning trend towards medicalising normal responses or emotional states, with such discourse now receiving widespread media attention (Jacob et al, 2013; DCP, 2013; The Guardian, 2013; The Economist, 2013). Others have focussed criticism on their utilisation *[being] sometimes used too loosely by clinicians, and too rigidly by regulators, insurers, lawyers and at times researchers, who afford it reference and deference disproportionate to its over acknowledged limitations* (Berk, 2013, p. 128).

1.3. Contemporary concerns surrounding psychiatric medication

Sitting within the broader context of the increased use of psychopharmacology in mental health services, it is noted that there has been a decrease in investment into new, more targeted or less toxic psychiatric drugs (Healy, 2009; Moncrieff 2009; Fibiger, 2013). As previously mentioned it is widely accepted in clinical practice that diagnoses such as 'schizophrenia' are heterogeneous. Alongside this still little is known about biological or genetic mechanisms of psychiatric illness. According to Fibiger (2013, p. 650) *'given that there cannot be a coherent biology for syndromes as heterogeneous as schizophrenia, it is not surprising that the field has failed to validate distinct molecular targets for the purpose of developing mechanistically novel therapeutics'*. The RDoC project represents a growth in the endeavours to link future disease classifications on the basis of neuroscience which

aim to encourage newer targeted medication therapies being developed, but this is still in its early stages (Cuthbert and Insel, 2010). Indeed other academic research is being published which is suggestive of the opposite perspective - that genetic and biological indicators are non-specific to symptom clusters and instead environmental factors are more likely to be relevant to describe this heterogeneity (Owen, 2012). Thus, at present, still not much is known about how to move forward in the development of more useful and less toxic psycho tropic medications, thereby remaining a blunt tool, with some proposing that any beneficial effects are attributable only to the sedative and tranquillising properties of such medication (Healy, 2009).

Over the last couple of decades there has also been an increased appreciation of mental illness in society and the burden that mental illness plays (Murray et al, 2013). According to the WHO, by the year 2020, if the current trends continue the burden of depression will be the second leading cause of disability adjusted life years lost (DALY) measure (Murray et al, 2013). The links between the trend of increasing prescription of certain psychiatric medications alongside the increasing social awareness of mental illness are uncertain. It is suggested by critics that there is a strong co production in knowledge between the medication and the roots of the disorder, via the marketing strategies of large pharmaceuticals and other bodies with vested interests (Moncrieff 2006, Rose, 2003; Pilgrim et al, 2011). For example Watters (2010) uses the example of depression in Japan to explore how psychiatric awareness and prescription rates are linked. According to the author depression was not recognised in psychiatric terms in Japan prior to the new millennium, with reference instead to descriptions of personality types, similar to the term 'melancholic'. However, an international consensus group was created to promote the psychiatric term of depression, alongside the marketing campaign of a large pharmaceutical company. Subsequently anti depressant use has dramatically increased since 2000. Rose (2003) eloquently emphasises this possible link, making is clear that the dominance of psychiatric medication has also impacted how both professionals and the lay person speak and understand mental illness: *So the debate cannot be only one of efficacy, as if illness, treatment and cure were independent of one another* (ibid. p.58)

Having said this, a body of criticism of psychiatric medication has been growing over the last 15 years also. Criticism of the role of the pharmaceutical industry in general, in prescribing behaviours and marketing has become increasingly popular. For example, the recent book by Ben Goldacre (2010) entitled 'Bad Pharma - How drug companies mislead doctors and harm patients' was one of the year's most popular non fiction books, receiving wide spread acclaim.

Within psychiatric medication management, there have been a significant number of legal cases which have brought anti depressant use into question, with large pay outs being settled by the pharmaceutical industry (see Rose, 2003). With anti psychotic use, there has been growing appreciation of the long term and serious nature of side effects. For example, recent research purporting the life expectancy for people diagnosed with psychosis to be 15 - 20 years less than for the general population, as a result of long term anti psychotic medication use, has been widely publicised (Healy et al, 2012; Whitaker, 2004; Thornicroft, 2011; Colton and Manderschied, 2006).

This was highlighted in the recent damning report by The Schizophrenia Commission which raised the serious concerns of physical wellbeing for those prescribed anti psychotic medication as one of the key areas for improvement in mental health service today (The Schizophrenia Commission, 2012). As such, there is a growing doubt by service users over the 'cost - benefit' ratio for psychiatric medication. While some service users find medication helpful, and are ready to put up with its adverse effects because of the beneficial impact, irreversible side effects, such as memory loss, or involuntary hand and leg movements, damage to liver and kidney functioning, are becoming more well known (Moritz et al, 2009; Healy, 2009). Of particular concern is multiple prescribing, or what is known as poly pharmacy. For example up to a third of users are being prescribed a total dose of anti psychotic medication above that deemed acceptable by the British National Formulary (Harrington et al, 2002; Healthcare Commission, 2007; Howes et al, 2012). This is compounded by the trend that prescription of new medication and increased doses of psychiatric medication are often given during periods of crisis, yet are less frequently reduced once the crisis is resolved. Policy guidelines have been issued in an attempt to counteract the issue (DH, 2013; NICE, 2009). Yet, poly pharmacy remains a concern in the field (Ito 2005).

A separate but related trend to consider for the context of psychiatric medication management is what has traditionally been viewed as compliance rates to medication regimes. Poor compliance historically has received much attention within the psychiatric literature, with reviews concluding that adherence rates for psychiatric medication regimes are far below those in physical medicine (Cramer and Rosenheck, 1998). Research suggests a lack of trust in the encounter. For example, in an examination of medication management practice, Read (2005) concludes that service users do not chose to involve or inform practitioners in the serious decision to come off psychiatric drugs and other research has been published which shows that many people chose to stop taking

psychiatric medication as a positive attempt to regain control (Britten, 2010; Roe et al, 2009).

Of final note here, there has been increasing acknowledgement of the detrimental impact psychiatric medication has in relation to stigma. The adverse effects of psychiatric medication may further magnify the otherness of the person experiencing mental ill health. The altered physical appearance as well as the difficulties in functioning, either a consequence of taking or aggravated by psychiatric medication, contribute to the external and internalised stigma of people with mental illness (Link et al, 2001; Pescodolino et al, 2007; Schultz et al, 2003; Corrigan, 2007).

1.4. Section summary

In summary, psychiatric medication continues to remain the key treatment modality in mental health treatment programs although psychological and psycho social interventions are increasing in support and availability. There nevertheless remains a dominance of the medical model of understanding mental illness. There is a growing body of evidence which raises doubt over the efficacy of psychiatric medication and also some highly worrying findings concerning long term side effects and quality of life, which seriously undermine the potential benefit for medication use. These are now relatively well known in the literature and there is increasing awareness in society. Recent historical shifts alongside the changing policy context of mental health services, and in particular the focus on personalisation, marketisation, medicalisation, alongside social inclusion, and personal recovery in mainstream discourse, paint a picture of a highly complex mental health system, where choice, collaboration, debate and discussion for medication management practice would appear at the forefront, but also where there remains existing power structures and many stakeholders with potentially conflicting aims. The next section further explores the model of personal recovery for UK mental health services, exploring the roots of the recovery movement, discussing its definition and describing contemporary projects underway in the UK to implement recovery ideals into UK mental health practice.

1.5. Recovery oriented services

Shared decision making has proposed to be a central tool for recovery oriented services (Deegan and Drake, 2006). This section discusses the origins and meanings of the concept

of personal recovery, exploring the policy context and recent initiatives towards promoting recovery oriented practice in mental health services.

1.5.1. The concept of personal recovery

A number of authors have highlighted the distinction between 'clinical' forms of recovery (associated with achieving a pre illness state, reduction in symptomology and preoccupations with cure to a condition) and the model of 'personal' recovery (Repper and Perkins, 2003; Davidson et al 2008c; Secker et al 2002; Slade, 2008; 2010). In the context of modern mental health UK policy, the term recovery is associated with the latter meaning: one which instils hope for the future and is a way of overcoming losses associated with being mentally ill. It emphasises the process or *journey of recovery* as something which is not static but moving and changing over time, being led by the service user in a re-evaluation of identity (Repper and Perkins, 2003). It has also been referred to as a 'consumer' model of recovery, to reflect its historical roots (see S. 1.6) and to highlight its '*individually defined and experienced nature*' (Slade, 2010, p.2).

By far, the most often quoted definition of recovery is that offered by Anthony in 1993:

...a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living in a satisfying, hopeful way and contributing to life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

(ibid, p. 527)

This quote emphasises the developmental journey that the model of recovery imparts. Others emphasise the importance of both *living with and living beyond* the adverse impact of a diagnosis, to lead a fulfilling life with hope (Davidson, 2003). Thus, the concept of a journey, of growth, optimism and hope is central to narratives of personal recovery. There is acknowledgement that people have to come to terms with the ordeal that the occurrence of mental health symptoms can have on their lives and incorporate these experiences into a new sense of personal identity, with belief and hope for the future and regaining a sense of control over one's life (Shepherd, Boardman and Slade, 2008). Leamy et al (2011) undertook a systematic literature review and identified more than 5000 articles. This extensive synthesis found that the recovery process comprised of: Connectedness (relationships, peer support and support groups, being part of the community); Hope and Optimism for the future (belief, motivation to change, hope inspiring relationships, positive thinking and dreams and aspirations); Identity

(dimensions, rebuilding, overcoming stigma); Meaning in life (spirituality, social roles and goals) and; Empowerment (control, personal responsibility and strengths), giving the acronym CHIME. Importantly this robust conceptual map highlights the importance of spirituality and social inclusion as important processes for recovery. The themes were similar across heterogeneous studies, including studies which explored perspectives of people of a BME origin, thereby offering a comprehensive framework from which organisational, social and psychological interventions can be targeted (see S. 1.7 below).

The recovery concept has also often been represented in terms of stages. For example, the validated STORI model shown in Table 1 below describe five stages, each requiring struggle and active participation (Andresen, Caputi, and Oades, 2006).

<i>Stage 1 Moratorium</i>
Denial, confusion, hopelessness, identity confusion and self protective withdrawal
<i>Stage 2 Awareness</i>
The person has a first glimmer of hope of a better life, and that recovery is possible. This can be an internal event, or it can be sparked by a clinician, or significant other. It involves an awareness of a possible self other than that of 'sick person. A self that is capable of recovery
<i>Stage 3 Preparation</i>
The person resolves to start working on recovering. This stage involves taking stock of the intact self, and of one's values, strengths and weaknesses. It involves learning about mental illness and services available, recovery skills, becoming involved in groups, and connecting with peers.
<i>Stage 4 Rebuilding</i>
In this stage the hard work of recovery takes place. The person works to forge a positive identity. This involves setting and working towards personally valued goals, and may involve reassessing old goals and values. This stage involves taking responsibility for managing the illness and taking control of one's life. It involves taking risks, suffering setbacks and coming back to try again.
<i>Stage 5 Growth</i>
The final stage of recovery could be considered the outcome of the recovery process. The person may not be free of symptoms completely, but knows how to manage the illness and to stay well. Resilient in the face of setbacks, has faith in his or her own ability to pull through and maintains a positive outlook. The person looks forward to the future and a positive sense of self.

Table 1. The stages of recovery model (STORI). Andresen, Caputi and Oades, 2006.

Whilst such models are useful, they have been criticised as being too linear, where instead a far more individual, overlapping and dynamic representation is warranted, allowing for the ups and downs of the typical recovery journey to be represented (Deegan, 1988).

For mental health services, recovery represents a transformation towards a new way of working, with service users moving towards the centre of the recovery process and where

decisions are based *less on professionally defined goals and more on listening to and acting on the service user's wishes* (Slade and Hayward, 2007, p. 81). Therefore recovery also represents the service user having expertise and knowledge, in addition to the ideas of regaining control over one's lives and future. As such, shared decision making is a fundamental tool for recovery oriented medication management practice (Deegan and Drake, 2006; Drake, Deegan and Rapp, 2010; Baker et al, 2013).

1.6. Historical roots and theoretical links

The historical roots and theoretical links with the recovery model are diverse and numerous. For mental health service users, the recovery model represents an international movement over the last 30 years, which has demanded that the voice of the service user be heard within main stream psychiatry. Over this time, a growing body of personal accounts of mental illness, as well as what is deemed as important and meaningful for personal recovery has emerged, with eminent authors such as Patricia Deegan and Judi Chamberlin in the US and Jan Wallcraft in the UK acting as figure heads for change (Chamberlin 1978; Deegan, 1988;1996; Wallcraft, 2002). According to Davidson there has been a war within psychiatry over this period and the recovery movement has the overarching aim to *afford people with serious mental illnesses the rights, opportunities and resources needed to lead meaningful and productive lives* (Davidson, 2010, p. 3). This trend links to wider changes in the disability user movements and the emergence of the social model of disability (see S. 1.1.1 above). The social model of disability has been hugely effective at emphasising a commitment to people's civil and human rights and social inclusion. However some authors have also noted key distinctions between the survivor movement and the social model of disability. For some, the importance of highlighting mental illness and distress in terms of personal experiences and perceptions differs from the social model of disability's acknowledgement of impairment (Beresford and Wallcraft, 1997).

Instead it is commonly acknowledged that recovery represents a civil rights movement stemming from the critical psychiatry movement, being strongly influenced by modern historical figures in psychiatry, such as Goffman and his work on 'total institutions' which highlighted the failings of psychiatric systems where the value of the individual was minimal (Goffman, 1961) and others such as Szasz (Thomas Szasz, 1920 - 2012) who criticised the moral and scientific underpinnings of psychiatry. As such, recovery is proposed by some as an anti thesis to the construction of power and authority in

traditional psychiatry (Stevenson, 2000). The recovery movement has been particularly useful in the highlighting problems associated with both, a dominance of deficit reduction models of psychiatry, as well as the fallacy of a system which focuses on abnormalising behaviours and creating difference to human emotions and behaviour (Stevenson, 2000; Rose 1986). For some there are proposed links between this movement and the ideals seen previously in history of psychiatric care towards 'moral or humane treatment' (e.g. Adolf Meyer, 1866 – 1950, see Davidson, 2010 for further review) and for others recovery represents a move back towards humanistic or even psychoanalytical approaches in psychiatry where respectful relationships and client focused therapies are valued (Carl Rogers, 1902 - 1987 - see Rogers, Kirschenbaum and Henderson, 1989).

It has also been suggested that there are strong links with the growing appreciation of positive psychology and a re- emphasis on personal strengths and wellbeing (Rapp and Goscha, 2012; Slade, 2010). Indeed if we look at the definition of positive psychology bestowed by Seligman and Csikszentmihalyi (2000) the conceptual similarity is striking, especially with its emphasis on hope and optimism for the future:

The field of positive psychology at the subjective level is about valued subjective experiences well-being, contentment and satisfaction (in the past) hope and optimism (for the future) and flow and happiness (in the present)

(Seligman and Csikszentmihalyi, 2000, p. 5)

However, it is also important to emphasise the links of the recovery model to the broader change in westernised societies towards neo liberalism and increased consumerisation of public services (see S. 1.1.). Ideals of patient centred care and personalisation may have at least encouraged the adoption of the recovery concept in modern mental health policy (DH, 2011a). A criticism of note here is that recovery in these terms risks forgetting the social elements of recovery (O Hagan, 2003). For example, Beresford (2002) suggests that these two divergent roots to the recovery model of mental health (neo liberalism and grass roots user movement) have resulted in different branches of the recovery model today - one being a consumerist model of recovery, being consultative and perhaps tokenistic in approach and the other representing a more democratic form of recovery, based more on civil rights and participatory ideologies. In addition, Campbell and Rose (2011) suggest that the radical beginnings of this latter recovery movement have waned. It has been proposed that recovery rhetoric may now have been adopted by established institutions of power and consequently is being used by people in authority to justify decisions (Pilgrim, 2005; Carey, 2009; Glover, 2012).

According to Pilgrim (2005):

...there is a tension between democratic impulses of the service user movement on the one hand and on the other, the agenda of the health care providers to co opt the service user voice in a corporate tokenistic effort to achieve a stated policy outcome .

(Pilgrim, 2005, pp. 17-26)

Criticism of the recovery model has also been received on other fronts. Most notably, there has been criticism that the definitions of recovery remain difficult to measure, being possibly too broad (McCranie, 2011). Ramon (2007) also points out that language in the Australian mental health policy literature echoed optimism and hope long before the recovery term was established in 2003, suggesting that the adoption of the term 'recovery' is not a prerequisite for positive change in the system.

Finally, it has been noted that while receiving widespread support in modern mental health policy, it still does not feature as a topic within the more 'traditional' peer reviewed literature in the professions. For example, in the fields of clinical psychiatry, recovery is still often referred to in clinical terms in psychiatric academic journals such as *American Journal of Psychiatry*, *Journal of Clinical Psychiatry* and for Clinical Psychology journals, such as *The Annual Review of Psychology* and *Psychological Medicine*. However there are some notable exceptions here, including many articles on personal recovery featuring in mainstream academic journals such as the *British Journal of Psychiatry*, *Schizophrenia Bulletin*, *Psychiatric Services* and the *Psychiatric Rehabilitation Journal* amongst others (McCranie, 2011).

In summary, challenges to embedding the recovery model remain, with agreement amongst many that these challenges continue to centre around the need to place equal value on both service user and professional knowledge and expertise in the mental health encounter:

The challenge coming from the service user movement, or at least significant elements of it, is twofold: First accept our understandings of our own experiences as equally valid as professional understandings. Second, acknowledge that our ability and expertise in self help and mutual support is commensurate to that of professional expertise. In short that service users are not merely consumers of mental health care and treatment but are primarily experts by experience.

(Campbell and Rose, 2011, p. 460)

In other words, the binding concept for recovery is grounded in the *simple yet profound realisation that people who are diagnosed with mental illness are human beings* (Deegan, 1993, p. 8) and hence have strengths as well as weaknesses and a future that does not need to mean continuation of a life as a chronic patient. This needs to remain at the forefront of policy and practice in mental health services.

1.7. Recovery in mental health policy and practice

As part of the transformational change underway within wider health and social care reforms (see above), the recovery model remains part of the key strategy for mental health policy (DH, 2011a), with an increased focus on wellbeing, awareness and personalisation. The increased focus within the national outcomes framework on non clinical outcomes, including psycho social indicators and service user's experiences has the aim of promoting cultural change (Naylor, 2012). Thus the concept of recovery has remained a priority in UK mental health policy:

'If adopted successfully and comprehensively, the concept of recovery could transform mental health services and unlock the potential of thousands of people experiencing mental distress'

(FutureVision Coalition, 2010; cited in Shepherd et al, p.2)

Indeed, the concept of recovery was already adopted by the National Institute for Mental Health in England (NIMHE) prior to the new millennium and has now been widely incorporated throughout overseeing professional bodies, including the Royal College for Psychiatrists, the British Psychological Society, Mental Health Nursing and Social Care Institute of Excellence (e.g. SCIE, 2007; DoH, 2006). Recovery rhetoric is now ingrained into professional discourse in mental health services.

More recently, well funded national projects have been piloted to embed recovery principles into practice. In particular, the Implementing Recovery through Organisation Change, project (ImROC) and the RE FOCUS projects are worth particular note:

The REFOCUS study is National Institute for Health Research (NIHR) funded research project. It applies an RCT design to explore the success of a pro recovery intervention for mental health professionals, in community mental health teams in London and Gloucestershire. A 12 month training and coaching program was co-produced and facilitated by service users with the aim to enhance skills of professionals to be able to better support people on individual recovery journeys. Evaluation data is yet to be

published but the intervention aims to target two domains; promoting values of personally defined recovery and pro recovery working relationships. A particular focus has been on exploring service users strengths and future goal planning as part of care programs is seen to embed the principles of the CHIME framework⁸ into mental health service provision (Leamy et al, 2011; Slade, 2013). This study has not focussed on social inclusion as part of the intervention/evaluation program.

Box 1: 10 Key organisational challenges

- 1) Changing the nature of day-to-day interactions and the quality of experience
- 2) Delivering comprehensive, user-led education and training programmes
- 3) Establishing a 'Recovery Education Unit' to drive the programmes forward
- 4) Ensuring organisational commitment, creating the 'culture'. The importance of leadership
- 5) Increasing 'personalisation' and choice
- 6) Changing the way we approach risk assessment and management
- 7) Redefining user involvement
- 8) Transforming the workforce
- 9) Supporting staff in their recovery journey
- 10) Increasing opportunities for building a life 'beyond illness'

(from Implementing Recovery: A new framework for organisational change, Sainsbury Centre, 2009).

Figure 1. 10 Organisational Challenges for ImROC. From Shepherd, Boardman and Burns, 2010, p.2

The ImROC program was initiated in 2009 and piloted intervention projects are underway nationally across 44 sites, with the aim of changing attitudes and behaviours of practitioners and the culture of organisations to be more supportive of recovery for people receiving services (Shepherd, 2013). Ten organisational challenges were identified as shown in Figure 1 (Shepherd, Boardman and Burns, 2010, p.2). This extensive program currently boasts the creation of 14 Recovery Colleges with co produced learning sets attended by thousands of people (practitioners and service users), briefing reports and guidance for services. The project has also assisted with the creation of 150 Peer Support Worker posts and 25 'Peer Educators' and a stated aim of the project is to increase the number of peer support workers to 50 % of the workforce. Locally, in Cambridge and Peterborough Foundation Trust (CPFT), ImROC has helped in the recruitment and training of 60 peers with lived experience in mental health problems and the majority have now been

appointed to paid positions within the trust. One of the stated aims of this program is to encourage diversity and recognise the *importance of lived experience in delivery of mental health services* (<http://www.cpft.nhs.uk/patients/peer-support.htm>).

⁸ See S.1.5.1. above

Whilst evaluation is ongoing and research exploring peer support workers is limited (Pitt et al, 2013; Trachtenberg et al, 2013), mental health services may benefit from introduction of peer workers by combating institutional stigma and creating new understanding and respect for different forms of expertise, assisting with overcoming inherent discrepancies in power and bringing experiential knowledge more to the fore of appreciation in the culture of mental health services (Shepherd, 2013; Repper, 2013).

Initiatives are also taking shape in other areas of the UK. In Devon the 'recovery oriented prescribing project' is promoting key competencies and skills for a recovery oriented approach in medication management practice (Baker, 2013).

Finally, the SHiMMe (Shared Involvement in Medication Management) project, led by Professor Shula Ramon is of note here. A three year NIHR funded project took place within the local mental health NHS trust implementing a piloted intervention program involving a training program for shared decision making to both practitioners and service users and a rigorous evaluation. The key aim for this project is to increase service users' ownership and control within medication management practice and to measure the therapeutic outcomes associated with the intervention.

However, while these projects represent examples of best practice in the UK, recovery oriented practice remains inconsistent in terms of implementing agreed principles of this approach (Shera and Ramon, 2013). In addition, as can be seen above, while these interventions are undertaking important work in the areas of improving working relationships and training and raising awareness, other aspects of recovery principles are yet to be fully tackled - i.e. social inclusion, wider community involvement and overcoming stigma.⁹

There is also caution about how the rhetoric of recovery is actually being absorbed within the wider mental health system, with fears the term recovery is instead being used as a tool to reinforce old ideals of compliance to service outcomes. For example, Turner, Crowson and Wallcraft (2002) present concerns from service users, that professionals may use recovery rhetoric to justify service outcomes. The authors found that service users were actually worried about not being compliant with their recovery plans as this may subsequently impact on their social welfare provision. As such there has been

⁹ Although a notable exception is the Time to Change campaign – see S. 1.1.1 above

growing critique surrounding what the recovery movement has achieved in terms of addressing structural inequalities.

Many mental health services, despite their articulation around a recovery orientation, still see that their core business remains to assess mental status, alleviate symptoms of distress, medicate, risk manage, monitor, review, plan, document, manage, care, refer where necessary and rehabilitate into the community. In this position, services have still seated themselves at the head of table as experts and managers of people's lives.

(Glover, 2012, pp. 30-31.)

As the above quote illustrates, there is concern that the discourse of partnership and collaboration can mask power imbalances and differing agendas, making no real impact on the clinical authority of the mental health worker or levels of service user empowerment. Nevertheless the growing awareness of recovery principles in practice, the ongoing interventions underway, alongside the centrality of recovery in mental health policy represent an important and positive contextual feature for appreciation in this thesis. Namely in exploring views of shared decision making in the context of a community based mental health team and investigating how psychiatric medication management practice occurs in practice.

1.8. Conclusion

This chapter has explained the broader context within which shared decision making for psychiatric management exists. The recent transformational shift in culture and policy, and the complexity present in the mental health system, is evident from the brief review presented here. As such the contemporary policy context highlights the relevance of this study. Of particular note is the growing awareness of serious concerns surrounding long term psychotropic medication use and the worrying trends towards increased diagnosis and prescription in the treatment of mental ill health. As such, research exploring SDM in this context is particularly timely. The final section explored in depth the historical roots and conceptual links of the recovery model. Shared decision making is proposed to be a key tool for achieving change towards recovery oriented practice in UK mental health service provision.

The subsequent chapter presents a review of the relevant literature. This begins with an overview of dominant models of decision making in healthcare. This is followed by a discussion and critique of the model of shared decision making. Research into SDM in the

mental health context is then evaluated. Gaps in the current literature are highlighted, and the research questions are described, highlighting the study's original contribution to knowledge.

Chapter Two. The Literature Review

Chapter outline

The chapter begins with an overview of dominant models of decision making in healthcare. This is followed by a discussion and critique of the model of shared decision making and an examination of broader constructs of collaboration and involvement to assist understanding about how decisions are made in mental health medication management.

The second part of this chapter explores the research that has examined decision making preferences and practice in mental health. This section explores how applicable models such as shared decision making are to making decisions about psychiatric medication as well as exploring barriers to achieving patient involvement in mental health. Gaps in the current literature are highlighted and areas where further research is needed are presented.

The chapter concludes by exploring how this thesis adds to the current research in the area, with a description of the research questions this thesis explores.

PART A: Healthcare Decision Making: Existing Models and Frameworks.

2.1. Introduction

In order to explore decision making processes for psychiatric medication management, it is first necessary to understand dominant and influential models of decision making in healthcare, more generally. There is a need to explore how these models may relate to the context of psychiatric medication management and how the wider decision making literature can help inform the conceptual framework for this thesis.

The first part of this section will briefly examine the dominant approaches in decision making theory. A critique will then follow of the main models of service user (see note re: terminology) involvement in doctor patient decision making, focusing predominantly on the influential Shared Decision Making (SDM) model. The section concludes with an exploration of the broader concepts of involvement and collaboration. These broader conceptualisations are seen as especially useful for exploring some of the important contextual elements relevant to this thesis and psychiatric medication management specifically. It is necessary to highlight from the outset of this review, that there is no

overriding consensus on the scope and precise definitions of many of the models presented. Indeed the nature of a model is such that its aim is to simplify and make abstract a complex and multi dimensional reality that it tries to represent. In the evaluation of any model, therefore, it is acknowledged that the complexity and experiential reality of the construct it represents, is largely lost. I nevertheless view this as a useful classification system to explore current understanding of ‘good practice’ or what is deemed ‘ideal’. A greater knowledge of these models and their specific limitations will therefore help inform the construction of new knowledge to the topic.

2.2 Decision Making Models in Health Care

Theoretical perspectives in decision making emerge from a wide variety of disciplines, dominating fields such as Psychology and Economics since the utility theories of the 1950s (see Goldstein and Hogarth (1997) for an in depth review).

Clinical decision making has been most influenced by the following theories:

- *Expected utility theories* which see decision making as related to its utility (or value) and its achievability (or tradeoffs). So in the context of clinical decision making, such theories help weigh up the pros and cons (such as side effects in choosing between multiple treatment options) to inform a rational explicit decision.
- *Information processing theories* (Newell et al, 1958), which explore factors which limit or affect rationality (such as cognitive load or the amount of information that can be provided for processing at one time)and
- *Social judgement theory* (Juslin and Montgomery, 1999) which explores the ‘lens’ of decision making and how to affect attitude change.

These models are all based on an individual perspective, with an autonomous subject being at the centre of the decision making process.

However, the key concepts, models and measures of patient decision making developed in psychology and economics do not necessarily translate to decision making in the context of chronic, long standing illnesses within diverse populations, and do not incorporate an understanding of the wider mental health system. These models are cognitive and de contextualised and generalising findings from controlled laboratory studies to complex real world examples is not necessarily appropriate or useful. In addition, factors such as; patient lifestyle; cultural influences; control of access to information are not taken into account. The significance of these models to informing predominant decision making interventions in the field should nevertheless be acknowledged. For example,

incorporating ideas such as the preference concept into decision making interventions and understanding how communication during the service user practitioner interaction influences the decision making process and the quality of the interaction (Wills and Holmes Rovner, 2006). However, in the context of building theory about decision making for psychiatric medication management, a *schema that, at least, includes decision making as relational, contextual and distributed is essential* (Murtagh, 2009, p.82).

Models that have explored the doctor - patient relationship and communication in relation to decision making, is also not a new area of study. The 1950s saw a new trend in important research focusing on the doctor patient relationship and interest has remained since this time (Wirtz et al, 2006). In recent years, however, and in conjunction with major policy shifts in healthcare provision (see chapter one) there has been increased interest in the literature exploring patient participation in healthcare settings. For example, there has been a fivefold increase in the number of studies exploring shared decision making between 1996 and 2003 (Makoul and Clayman, 2006).

At present, there are four broad categories of patient-doctor decision making models (Wirtz et al, 2006; Charles, Gafni and Whelan, 1997; 1999; Emanuel and Emanuel, 1992). These are represented in Figure 2. Generally, these models fall within a spectrum which varies with respect to the level of patient participation or autonomy in the decision making process and the role of the practitioner. Each model therefore is based on a set of assumptions regarding the roles of the patient and the doctor. Specifically, the models make assumptions about the extent to which the patient and doctor have responsibility, involvement in decisions and choice over the treatment option.

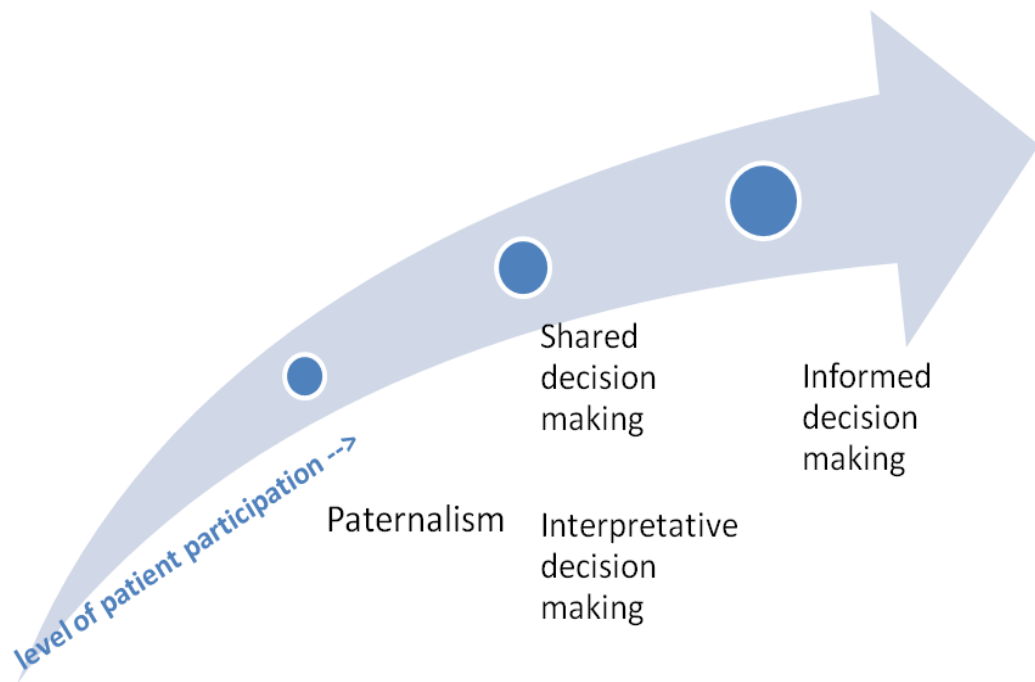


Figure 2: Models of patient - doctor decision making

In the traditional paternalistic model the doctor makes the decision, after evaluation of the diagnosis, the treatment options and risks and benefits for these outcomes. This model assumes that the doctor has the duty to act in the best interest of the service user and that the patient is not able to make the decision due to their lack of capability or lack of relevant knowledge. It has been suggested that paternalism is derived from the biomedical paradigm of health related decision making, prioritising scientific evidence and professional expertise. Here, less emphasis is placed on the patient's values, lived experience or life goals (Russell et al, cited in Sandman, 2011). It is also associated, with the compliance paradigm, where the patient is subservient, following somebody else's ideas. Non compliance in this model then would be deemed problematic (Sandman et al, 2011). At the other end of the spectrum the informed decision making model assumes that the service user has ultimate accountability and responsibility for the decision made. Here, the professional acts as an adviser to the process, ensuring the decision made is informed and the service user has all relevant information.

In the middle of the spectrum on levels of participation, the interpretative model, like paternalism, is also based on the assumption that the doctor has the duty to reach the decision, but focuses on taking additional information such as the patient's preferences and values into account. Within the shared decision making model, the focus for patient autonomy is more flexible and less black and white than both paternalism and interpretative decision making on the one hand, and informed decision making on the

other. Here, communication and shared deliberation are sought in the decision making process and the involvement of the service user and sharing of preference and values are essential to the end shared decision. It is associated with the shift towards the concept of 'adherence' or 'concordance', emphasising the active role of the patient alongside placing value on the expertise brought by a service user to the health care encounter (Sandman, 2012; Marland, 2005; Coulter and Collins, 2011) .

2.3 Shared Decision Making – a more detailed examination.

For many,.. shared decision making is a philosophy as well as a way of doing things. Central to it is the belief that patients have a vital role in the decision making process; that their values and self-determination need to be considered equally alongside scientific knowledge.

(Da Silva, 2012, p. i)

Shared decision making (SDM) has become a term that has received widespread attention both in UK health policies and research literature exploring healthcare decision making (Coulter and Collins, 2011; DH, 2012a; 2010). As discussed in the previous chapter, but considering the health context more widely, shared decision making has been influenced by such factors as:

- changing societal attitudes surrounding patients' rights,
- cultural changes in attitudes towards healthcare services
- growth in the advocacy of community support and patient groups
- and increasing litigiousness

(Higgs et al, 2008).

In the UK, recent health care policy and legislation, alongside the rhetoric of increased choice, there have been increased obligations to increase involvement of patients in decisions about treatment and care and shared decision making has been used as a central tool of such changes (DH, 2012a; 2010). These shifts have been reflected in good practice guidelines for psychiatric medication management (National Prescribing Centre, 2007;2008; NIMHE, 2005; NICE, 2009a; 2009b; Harris Baker and Gray, 2009; Healthcare Commission, 2007; The Schizophrenia Commission, 2012).

SDM is not only valued as an ethical ideal, but also because it is thought to be related to positive health outcomes. There is, for example, evidence that SDM results in greater patient satisfaction and collaboration (Cox et al 2003; Swansson et al 2007) and is

particularly beneficial for long term decision making (Joosten et al, 2008). For decisions made about psychiatric medication, SDM is seen to offer a particular opportunity, given their complexity, and the trial and error nature of the process (see S. 2.6). This is coupled with the increased public concerns surrounding both the adverse effects of psychiatric medication, and the particular issues of poly pharmacy and high dosage prescribing present in psychiatric medication management practice in the UK (Morrison et al, 2012; Whittaker, 2004;2005; Healy et al., 2012). However, whilst research interest has increased in this field in recent years there remains a lack of consensus on a precise working definition for shared decision making (Barry et al, 2011; Edwards and Elwyn, 2009; Makoul and Clayman, 2006).

As shown in Figure 2, in terms of levels of service user involvement and responsibility in decision making, SDM has been proposed to occupy the middle ground between paternalism and informed choice. It has been proposed that there is a considerable overlap between SDM and terminology such as concordance, evidence based patient choice, enhanced autonomy and mutual participation (see Makoul and Clayman, 2009; Wirtz et al, 2006) and these concepts have been proposed to sit within the wider shared decision making model (Coulter and Collins, 2011).

Shared decision making was first defined in 1982 in a report exploring informed consent written for the US Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research:

It will usually consist of discussions between professional and patients that bring the knowledge, concerns and perspective of each to the process of seeking agreement on a course of treatment. Simply put, this means that the physician or other health professional invites the patient to participate in a dialogue in which the professional seeks to help the patient understand the medical situation and available course of action, and the patient conveys his or her concerns or wishes. This does not involve a mechanical recitation of abstruse medical information, but should include disclosures that give the patient an understanding of his or her consideration and an appreciation of its consequences.... Shared decision making required that a practitioner seek not only to understand each patient's needs and develop reasonable alternatives to meet those needs, but also to present the alternative in a way that enables patients to choose one they prefer. To participate in this process, patients must engage in a dialogue with the practitioner and make their views on well being clear.

(ibid, p. 38 and 44)

The emphasis within this definition is on SDM being very much a process based on the values of mutual respect and partnership. Other theorists have further elaborated on this

initial concept of SDM. A popular definition commonly cited in the literature is that of Charles, Gafni and Whelan (1997;1999). Here four characteristics of shared decision making are proposed:

- (1) that at least two participants—physician and patient be involved;
- (2) that both parties share information;
- (3) that both parties take steps to build a consensus about the preferred treatment; and
- (4) that an agreement is reached on the treatment to implement.

According to Charles, Gafni and Whelan (1997;1999) the defining characteristic of shared decision making is its interactional nature. Within this, there is the prerequisite that there are legitimate treatment choices. In addition, each person has to be both willing and actively engage in the process of exchanging information and sharing preferences. However, some disagreement exists as to whether this process in itself is enough in order to view the interaction as SDM. There is a lack of support for the model's premise that shared consensus has to be reached in order for it to be seen as SDM. According to the authors, if consensus on the decision does not occur, even if the process itself is collaborative, it cannot be considered SDM. Another limitation of this definition is that it does little to explain the process of acting as equal partners in reality, as it does not acknowledge or offer solutions to the inherent power imbalance in the relationship between the doctor and the service user.

An alternative integrated model, proposed by Makoul and Clayman (2006) has been a useful guide for exploring some of these concepts within the SDM literature further. Here, a systematic review of 418 articles was undertaken and a full analysis of the conceptual framework for SDM conducted. The subsequent integrated model of SDM proposed by these authors comprises of 'essential' and 'ideal' elements. The essential elements¹⁰ considered necessary for SDM to be deemed as taking place comprise of *the need to*:

- Define and explain problem
- Present options
- Discuss Pros / Cons
- Patient values / preferences
- Discuss patient ability / self efficacy**
- Doctor knowledge/recommendations
- Check/Clarify understanding

¹⁰ Note, written only for practitioners

- Make or explicitly defer decision
- Arrange follow up

** concept added by Makoul and Clayman (2006, p.305)

Interestingly the authors refer to the concept of self efficacy as a requirement for SDM. This term is proposed by the authors as an alternative way of explaining the need to discuss patient preferences and values, but specifically refers to the importance of understanding the patients' outcome and efficacy expectations, as laid out in Bandura's social cognitive theory, which have previously been linked to various behavioural outcomes (Bandura 1997). According to Makoul and Clayman (2006) then, the need to discuss the patient's beliefs about how capable they see themselves in being able to succeed and carry out the actions under discussion is an essential component to the SDM process.

The authors also acknowledge that the physician will often take the leadership role in the process, with medical knowledge in addition to the asymmetry in the provider – patient relationship resulting in the balance *being always or nearly always tipped in favour of the practitioner* (ibid, p.307). On this point, it is interesting to mention that this model, whilst noting the importance of '*patient values and preferences*', does not see the patient's experiential understanding or knowledge as essential to the process (even though '*doctor knowledge*' is present in the essential elements). In fact, the authors instead suggest that SDM does not require that practitioners need to relinquish control or decision making authority. For example, they comment that SDM can occur even if patients ask physicians to take decision making responsibility, provided that the essential elements are present. Also of note is the fact that the concept of mutual agreement is, in this model, marked as an ideal and not a required component of SDM (as oppose to that of Charles, Gafni and Whelan, 1997;1999).

Overall, the concept of shared decision making is a relatively fluid term, being not fully agreed upon within the literature. The hallmark but often implicit feature that appears through the models, is that both the patient and the practitioner have an equally valuable contribution to the decision making process. The term a "meeting between experts" may be especially pertinent here then.

2.4. Critical considerations

As eluded to above, the main defining characteristics of shared decision making is its interactional nature and the value it places on an equality of different types of knowledge. This is both its main strength and weakness. Important barriers between theory and practice currently exist, and the true complexity of how decisions are made or what structural and individual constraints need to be overcome in order to move towards the idea of a “meeting between experts” is not fully encapsulated by the model.

There is a lack of detailed understanding of what is meant by the sharing of the decision and the process that this involves in practice. Terms such as ‘negotiation’ or ‘mutual discussion’ are often used but do not elaborate on the deliberation that occurs during the encounters and how to balance the differing requirements of the healthcare consultation.

The model is based on important ‘unspoken assumptions’ which are not explicitly addressed or elaborated upon in these models. For example, Wirtz et al (2006) makes the point that, in addition to patient autonomy or involvement, there needs to be an acknowledgement of an additional assumption: *‘the accountability of professionals’*. At the heart of these models is the differing scope of doctor and patient power and responsibilities (see theory chapter for further discussion). This in turn links to the differing levels of accountability for these key stakeholders and other external influences, e.g. the wider culture, institutional practice, the societal expectations. Here Wirtz et al (2006) argue that unless these wider influences made explicit, SDM models will continue only to act “*as lip service to the decision making process*” (ibid; p. 122). Therefore, to increase understanding of decision making further it is proposed that the differing and often conflicting demands from system, policy and professional influences need to be made more open in the decision making process (Wirtz, 2006).

More generally however, the model needs to make more explicit what barriers exist (and therefore may need to be overcome) in order to uphold respect and recognition for the value of different forms of knowledge in the decision making process. Linking in with Wirtz’s point above, at the forefront of these is the inherent power imbalance present between patient and doctor in the healthcare encounter and therefore this needs to be made more explicit by the SDM model. Prevalent paternalistic cultural norms such as the “doctor knows best” and patients “do as they are told” mean that power relations will continue to shape the experience and outcome of the healthcare encounter (Murtagh, 2009). This, in addition to a consideration of cultural components of the contemporary U.K. mental health system and its broader historical context, impact on how power may be

shared in reality (see chapters one and three, for further discussion). More broadly, there is recognition that structural constraints such as class and education, in addition to people's previous experiences, may all impact on the mutuality and preferences towards levels of participation in an encounter (Elwyn, 2009). In addition, levels of involvement may fluctuate over time and change according to the seriousness of their condition (O'Grady, 2010).

In such a complex process, it is easy to see how engagement may, at times, be difficult and why such models are not being taken up in practice. For example, it has been found that even when doctors explicitly support patient's right to autonomous choice, this is often not reflected in their actual practice (Agledahl, 2010; Karnieli Miller, 2009). More fundamentally however, it has been suggested that unless the process of patient involvement and the process of communicating with the medical practitioner is seen as part of the therapeutic process, as opposed to an additional support to care, then such a complex and demanding process will not be embarked upon (Wirtz et al, 2006). In other words, whilst SDM is an ideal concept within medical ethics, unless the values it represents are embraced throughout care, then the value of this model may be relatively arbitrary.

2.4.1 Summary

In summary, different models of decision making exist in the literature. Both the informed and shared models of treatment decision making were developed largely in reaction to the paternalistic models, reflecting broader change towards 'patient led' care. Shared decision making is seen as the ethical ideal standard for health care practice, focussing on the exchange of expertise and information and joint weighing up pros and cons of a decision. Its value remains the acknowledgement of the different forms of knowledge in the encounter and enabling experiential knowledge to move more towards the fore (Charles, Gafni and Whelan, 1999; Whitley and Woltmann, 2010).

However, the most substantial criticism of the SDM models for healthcare consultations generally is that it does not encompass ideas that decisions are made over time in a complex interplay between multiple stakeholders. The rationale for SDM as a model may be a valid one in medical decisions where there is choice from several treatments options (Montori et al, 2006). But for people who may have been marginalised by society, deprived of agency and self-efficacy by previous encounters with the mental health system (see

context chapter) additional support may be needed to bring service user perspectives and preferences to the fore (Whitley and Woltmann, 2010). The tendency for models to avoid the full context and reality of the situation presents the additional danger of enlarging the gap between medical ethics and theory on the one hand and practice on the other (Matthias et al, 2013; Agledahl, 2010; Karneli Miller, 2009).

In conclusion while being influential and seductive in nature, the models discussed in this section are essentially 'transactional' in nature, focusing only on a narrow range of requirements, actions and behaviours (Trede and Higgs, 2008). The models fall short in considering how various structural factors, interests and motivations influence the decision making and how thoughts, feelings and longer term relationships may facilitate or hinder outcomes. According to Trede and Higgs (2008), with whom I agree, models of patient involvement need to incorporate a more critical and complex contextual understanding of decision making in health care generally (and for medication management in mental health, more specifically). In order to do this, it may instead be useful to focus on the answers to the following questions:

Who defines the problem? What options are being considered? How are service users' values and views incorporated into the discussion? What knowledge counts?

It is only through the critical appreciation and reflection by practitioners of these issues (as opposed to a list of requirements as proposed by SDM theorists), that transformative change towards a democratic collaboration between practitioner and patient may occur.

2.5. Moving towards a broader conceptualisation of involvement

Before the research exploring service user involvement in psychiatric medication management is discussed, broader conceptualisations of collaboration and patient involvement are considered.

2.5.1 Collaboration

Collaboration may be seen as distinct from SDM in that it refers to working together in the pursuit of shared goals, *where the participants have a level of equality and where there is a less clearer division of labour* (Dillenbourg, 1999, p. 8). As such, collaboration describes a more general approach or style of working whereas SDM focuses specifically on the

pursuit of reaching a decision. Unlike shared decision making which focuses on an event in time, collaborative decision making is a process of engagement with action plans under regular review. The model focuses more broadly on problems that emerge from both medical and non-medical issues. That is to say, the resolution of these problems may address the medical issue but within the context of broader health or life goals (O' Grady, 2010).

Although distinct, shared and collaborative decision making do not necessarily compete but may be seen as complementary approaches contributing to the emergence of well-balanced partnerships between patients and health professionals. Gray (1989) defines collaboration as *"a process through which parties who see different aspects of a problem [or issue] can constructively explore their differences and search for solutions that go beyond their own limited vision of what is possible"* (ibid, p.5).

According to O'Grady (2010), the increased focus on non medical perspectives may be especially relevant for patients with complex chronic conditions or people taking multiple medications and experiencing a wide variety of symptoms. As such, collaborative decision making and increased focus on health related goals is highly relevant to the context of psychiatric medication management (see chapter one). However the question nevertheless remains, how to achieve this state of partnership working detailed within collaborative approaches to decision making?

This question is addressed further by Trede's doctoral research that explored the importance of reflection for practitioners moving towards collaborative decision making (Tredes and Higgs, 2008). According to the model of 'critical collaboration' proposed by the authors, the first essential requirement for collaborative decision making is the need for a critical self awareness of what is motivating professional bias, professional authority and role thereby illuminating the various interests and interpretations underpinning practice.

Within this framework, the practitioners sought to share knowledge and power with patients, placing value on the patients input to the decision making process. According to Trede and Higgs (2008):

...making intentions and arguments for decisions transparent is key for truly collaborative decisions... In addition, collaborative decision making requires critique (including self critique) and moderation of interests, values and expectations of all parties involved in the decision making process, and safe, democratizing and caring environments to foster open transparent collaboration where patients feel they are

listened to and taken seriously'

(ibid, p.46).

Overall, factors that were found to be related to participation in collaborative decision making included: appreciating patients perspectives; becoming self aware of personal bias; providing opportunities for patients to participate; being willing to reconsider treatment choices; exploring options with patients; establishing reciprocal relationships; being open; teaching and learning from each other and recognising clearly the values of informed decision making.

Comparing these items then to the SDM model, many are overlapping and complementary items (for example, exploring options with patients, providing opportunities for patients to participate and appreciating patients' perspectives etc.). Where this model of critical collaborative decision making however differs (or at least elaborates on previous models), is the emphasis on the importance on critical self reflection in the process of collaboration and the need to make explicit the power imbalance and professional bias for scientific based knowledge. This self reflection assists the move towards a more equitable relationship with patients, where different types of knowledge and understanding are incorporated into the decision making process. The emphasis on decision making as a process over time is also recognised in this model. This critical approach to exploring collaboration is thus able to overcome some of the concerns about what degree of collaboration is appropriate, in which situation, and for which patient, by making the degree of collaboration for a particular situation more explicit.

Collaboration is a useful concept for exploring decision making mental health medication management. Although the term is somewhat overused in practice with many differing meanings, it is a useful concept in that it is more readily able to explore decision making as a process over time as part of the wider practitioner patient therapeutic relationship. Trede and Higgs (2008) explore how skills such as critical self reflection may be key for understanding how collaboration may be implemented in practice, allowing for bias inherent in the healthcare system to be made more explicit and for dialogue for decision making to be more open and honest.

2.5.2. Patient Involvement

Entwistle and Watt (2006) provide another broader model of patient involvement, inviting more complexity and sophistication in conceptual understanding. As shown in Figure 3, the authors focus on exploring patient involvement from the perspective of not only what people do or say in any given decision encounter, but also by incorporating people's views and feelings about their roles, efforts and contributions relating to the decision making and their relationship with the practitioner.

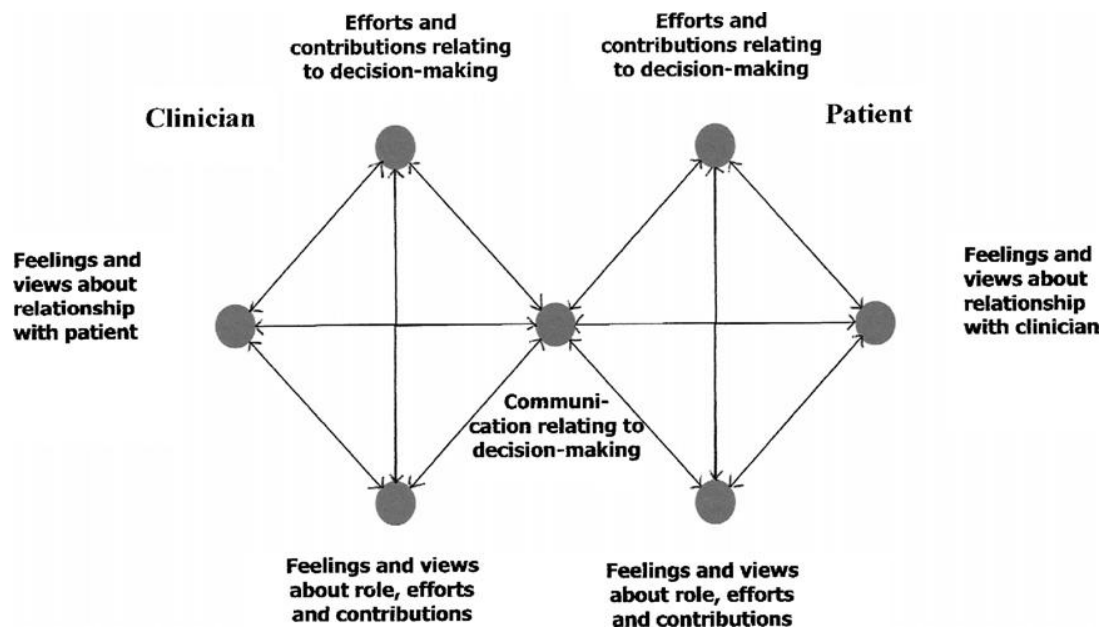


Figure 3. Aspects of involvement (Entwistle and Watt, 2006, p.273)

This model is interesting; firstly, as it broadens the understanding of what service users being involved in decision making includes; but secondly, because it visually represents the service user and clinician as equally contributing to the process. The model, by focusing on feelings and views about roles and contributions in the process also allows reflective processes such as *being in control* and *having an influence* to move to the forefront of understanding. This focus on individual views and feelings of involvement in decision also appears to reflect how mental health service users and practitioners encapsulate and describe being involved (Woltman and Whitley, 2010; Davidson, Miller and Flanagan, 2008; Shepherd, Boardman and Slade, 2008). Moreau et al (2012), in a recent focus group study of patient's experiences also found SDM to comprise of emotional, aesthetic and social and value oriented components. Here, patients were more concerned with the affective aspects of the decision rather than the informational or technical components.

Entwistle and Watt (2006) suggest that most research in this area has either explored the communication of the decision making encounter, or focused on how to encourage patients' efforts and contributions to the process. Instead this model supports the emerging literature which places increasing emphasis on recognising the importance of the '*clinicians efforts and contributions to decision making*'. For example exploring the importance of clinicians' attempts to understand the problem in light of their professional knowledge and the patient's perspective, and their efforts to ascertain and respond to the patient's needs and preferences. As such, this conceptual model helps assist the process of understanding what components are necessary for the resultant 'meeting of experts', thus moving beyond the narrow conceptualisation of SDM focussed on requirements related to practitioner communication and service user behavioural contributions.

2.5.3. Summary

Decisions concerning psychiatric medication often involve many different participants and often occur over long periods, in a lengthy process of trial and error. Broader conceptualisations of collaboration and patient involvement may be particularly useful to consider in the context of psychiatric medication management, exploring how partnership may be forged and how the ideal of a 'meeting of experts' may be achieved in practice. However the policy context, the growing recognition of the importance of shared decision making in professional discourse, and the emphasis it places on valuing experiential knowledge in psychiatric medication management practice, results in this being a central concept for this thesis to explore.

Part B – Research into Shared Decision Making in mental health services

2.6. Opportunity for SDM

"SDM reflects the values and processes of client centred care, evidence based medicine and the recovery movement"

(Adams and Drake, 2006, p. 1)

SDM in psychiatric medication management represents part of a larger change in the mental health system. As discussed in the previous chapter, in addition to the wider changes towards 'patient centred care', SDM is also a central tool for models of personal recovery and recovery based practice in mental health¹¹ (Schauer et al, 2007). Indeed, Deegan and colleagues suggest that: *"SDM is congruent with the foundational tenets of the consumer –survivor movement"* (Deegan, Drake, Rapp 2010, p. 7). Accordingly then, SDM for medication related decisions is one tool in a larger system which focuses on giving the mental health service user choice, enhanced control, placing increased priority on partnership with practitioners as part of a personalised approach (Shepherd, Boardman and Slade, 2008). Here the service providers and prescribers' role is to assist in the process of individual led recovery and the corresponding change in the service users' re evaluation of identity (Shepherd, Boardman and Slade, 2008). However as discussed in the previous section, whether prescribed shared decision making models are the most appropriate constructs for such principles is more questionable, with other concepts, such as collaboration, perhaps better fitting with the ideals of the personal and ongoing journey of recovery.

Nevertheless concepts such as shared decision making and collaborative decision making have become popular terms within mental health policy. However they have originated from other areas of medicine. Compared to other fields of health care, less is known about SDM in mental health service contexts. The studies that have been conducted show that mental health service users are keen to participate in decision making and desire greater involvement (Hamann, 2005; Loh et al, 2007a; Say, Murtagh and Thomson, 2006; Adams, Drake and Welford, 2006). Positive impact of SDM has been shown for improved treatment adherence, satisfaction, knowledge, involvement in decision making, reduced drug use and a trend for reduced hospitalisation (Hamann et al, 2007; Clever et al, 2006; Loh et al 2007b; Joosten et al, 2008; 2009). Other reviews show that when people are given greater choice in decisions, positive outcomes are observed (Davidson et al, 2012a). However, research is limited. This was highlighted by the recent Cochrane review, which only identified two studies for inclusion¹² in their review of shared decision making interventions within mental health services (Duncan, Best and Hagan, 2010).

Despite the apparent opportunity for SDM in mental health, some ethical concerns have been raised about the decisional capacity and capability of patients in mental health to

¹¹ See Chapter One for further discussion

¹² Studies which did not adopt a randomised control trial design were not included

effectively participate (e.g. Appelbaum et al, 2006). Practitioners have expressed scepticism about ability to participate due to cognitive deficits. However, involuntary mental health treatment is contrary to the value placed on service user autonomy and experiential knowledge, within SDM concepts. In addition, these views are incompatible with evidence that shows service users are capable of participating in most decision making situations (Loh et al, 2007a).

It is this background which means that it is necessary to further explore the value of SDM for mental health and more specifically medication management in mental health, providing a more comprehensive picture of what aspects of involvement are important and what barriers currently exist to implement SDM in practice. In short, a fuller contextual understanding is necessary to build a richer and more relevant understanding of SDM for psychiatric medication management.

Whilst the context chapter explores some of the defining features of medication management in mental health in more depth, for the purposes of this chapter, the below bullet points assist in understanding some of the complexities of the decision making process in psychiatric medication management:

- Medication continues to remain the key treatment modality in mental health treatment programs (Healy, 2009).
- Historical dominance of medical model of understanding mental illness (although see point 8 below) (Shorter, 1997; Davidson, Rakfeldt and Strauss, 2010)
- Historically poor compliance rates for psychiatric medication (above 50%) (Healy 2009).
- A shift from a 'compliance' to a 'concordance' paradigm in prescribing practice (Sandman, 2012)
- Serious and enduring side effects associated with psychiatric medication. As such, side effects may create a set of new problems and act as a deterrent to taking the medication on a continuous basis. Furthermore, a number of the side effects are irreversible, such as memory loss, or involuntary hand and leg movements, liver and kidney functioning etc (Healy, 2009)
- High dose prescribing and poly pharmacy are known problems in the field (Ito et al 2005)
- Changes to self identity in psychiatric medication taking (also see point 10 below)
- Psychiatric medication does not offer a 'silver bullet' for mental illness

- Recent shift in values towards recovery oriented prescribing and the adoption of the ‘recovery model’ in mental health
- Shift in values and attitudes towards the role of medication in mental health treatment programs and the growth of the bio-psycho-social model of understanding mental illness (e.g. see Whitaker, 2004)
- Stigma surrounding use of psychiatric medication (Malpass, 2009)
- The enduring nature of mental illness.

This remainder of this section will review the research that has explored shared decision making in mental health services. Preferences and perspectives of service users and practitioners towards involvement and practice of decision making will be presented, exploring the known barriers and facilitators. In addition, studies, which have explored the current practice of psychiatric medication management, are described.

Overall, four categories of research have been undertaken in this area:

- Exploring the preferences of service users in decision making process
- Exploring the views of mental health practitioners
- Investigating current decision making practice in mental health
- Exploring the efficacy of interventions or decision aids aimed at increasing levels of participation in decision making.

In this section I focus on reviewing the literature in the first three areas. Although the development of decision aids and bespoke interventions aimed at promoting shared decision making in practice is a worthwhile and practical application of theory in this area I argue that the knowledge base in this area is limited. As such this study has the aim of building theory, focusing on preferences, experiences, views and attitudes towards decision making alongside an examination of current practice. Increasing knowledge in this area will enable interventions to better target change in this field. Consequently, this review will not incorporate the decision aid and other intervention research.

2.7. Service user views and experiences

As alluded to above, there is mounting evidence that mental health service users (MHSUs) value participation in decision making and endorse models such as shared decision making (Adams and Drake, 2006; Deegan and Drake, 2006; 2008; Drake Deegan and Rapp, 2010; Hamann, 2005; Patel, 2008, Loh et al, 2007a; Say, Murtagh and Thomson, 2006). It

has been suggested that the desire for increased involvement in decision making may in fact be greater than in other areas of medicine (Douglas 2004; Hamann, 2005).

Motivations for this appear to be based on:

- past experiences
- a desire for recovery and a recognition of strengths (Mahone et al, 2011)
- The existing evidence concerning the achievements of the recovery approach (see context chapter)
- Types of decisions that are made are complex and multifaceted

(Patel, 2008).

This being said there is relatively little actual research which explicitly explores MHSU views in-depth about decision making for psychiatric medication management; or the facilitators and barriers to achieving a shared dialogue. Although the research suggests that service users want to be more involved in the decision making process, the exploration of meaning for service users in the context of making decisions about psychiatric medication needs expansion. However a few studies of note are important to consider at this point:

Simon et al (2007) undertook qualitative interviews with people receiving services from their GP for depression. This study highlighted that service users had a number of unmet expectations in their consultations regarding treatment. The first concerned expectations for more time in consultations, and the establishment of a trusting relationship with the GP. The formation of a trusting relationship was seen as very important during more difficult times, when service users reported wanting the doctor to take more of a leadership role. In addition service users expected the GP to be the main source of balanced information about depression treatment options, yet felt that, in general, they did not receive enough information, especially concerning side effects of proposed medication options. Fears and concerns about side effects alongside fear of stigmatisation of medication taking were raised as concerns by service users.

Tanenbaum (2008) used focus groups to explore types of information MHSUs value and what role it serves in decision making. The results showed that service users have a strong desire to know more about their condition and be involved in making decisions about treatment. People gathered information from multiple sources including the care team, other professional groups (such as pharmacists), peers and the internet. In general people valued scientific evidence although this also did create some problems in that this

sometimes reduced the value of the individual accounts. Most importantly, perhaps, focus group members referred to the importance of individuality and the need to treat it as part of the recovery journey where they are themselves an expert. Here again having trust with the practitioner was essential to success.

Mahone et al (2011) in a mixed stakeholder focus group study found that MHSUs supported SDM, and in particular the value it placed on '*putting consumers at a place where their voice is heard*' (ibid; p. 9). Service users valued being respected and listened to in the decision making process, although acknowledged that this was associated at times with raised fears about the increased responsibility this implied. Barriers raised to SDM in this study included previous experiences of coercive practice and the associated trauma for the service user.

Tee et al (2007) presented results from a cooperative inquiry study of student community psychiatric nurses and service users which explored service user participation in decision making. Themes that emerged as inhibiting participation included stigmatization and paternalistic approaches where diagnosis was used as the basis for clinical judgments. Factors enhancing participation included a respectful culture that recognised service users' expertise and communicated belief in individual potential. The importance of recognising power issues in these helping relationships was highlighted.

Finally, Whitley and Woltmann (2010) conducted 16 in depth qualitative interviews exploring the views of mental health consumers towards SDM. The results of this are interesting in that, whilst on face value, the results endorsed a shared approach to decision making, the meaning assigned to SDM was not necessarily congruent models presented in the previous section. Instead a slightly more complex picture emerged. The authors found that consumers often describe the preference for a two phase process which first prioritises autonomy but then, if that is not possible, defers to the clinician's judgement in more challenging or complex decisions.

According to both Simon et al (2007) and Woltmann and Whitley (2010) then, MHSUs are mostly concerned with SDM in respect of the level of control and autonomy over decisions, but are also suggesting the need to be flexible about this depending on the nature and complexity of the decision to be made. Trust and the importance of the therapeutic relationship in this process remain important themes throughout all of the above mentioned studies.

Davidson Miller and Flanagan (2008) further highlighted helpful relationships. This study was a synthesis of qualitative narrative interviews with service users, focussing on perspectives regarding the utility of treatment. Personal narratives focussed on the positive and helpful role of relationships for medication management. People discussed the prolonged process of first finding the right doctor or nurse, and then eventually the right medication. This study found that *the right prescriber was someone who listened to the person, was willing to try different things and who viewed the medication as more than just a way to reduce symptoms* (ibid, p.180). Involvement in decision making then is seen as reflecting the ideals of a trusting, open and honest relationship with clinicians where the service user is empowered and treated as an equal in the decision making process. It has indeed been suggested that the mechanism by which the therapeutic relationship positively impacts on recovery outcomes in mental health, is via its influence on increased agency and empowerment in decision making (Street et al, 2009).

Other research in this area has explored MHSU's experiences of psychiatric medication taking in the context of the recovery journey. This research emphasises that the decision making process is complex and varies according to the individual, their goals, priorities and values, in addition to their previous experiences of the mental health system. Research suggests that service users appear to value the importance of medication in mental health treatment programs. Yet, medication while being helpful at times, at other time may hinder recovery both as consequence of adverse side effects, and by undermining individual autonomy and responsibility (Baker et al, 2013). Medication may also negatively impact self image and identity (Malpass, 2009; Kartalova-O'Doherty and Tedstone Doherty, 2010). The influential writings of Deegan, Drake, Adams and Mistler explore the concepts of recovery in relation to medication decisions further (Deegan and Drake, 2006, Deegan, 2007; Deegan et al 2008, Adams and Drake, 2006; Mistler and Drake, 2008; Drake et al, 2009). Service users may develop and refine medication strategies over time, gradually accumulating expertise, customising their medication use in response to mental states and life events, and integrating flexible medication use into broader "personal medicine" strategies (Deegan, 2005; 2007; MacDonald-Wilson et al, 2013). Here medication is viewed as one tool in a larger toolbox of personal medicine, where the person finds the *right balance between what they do to be well and what they take to be well* (MacDonald-Wilson et al, 2013, p. 263). Many personal strategies are highlighted, which may not fit into medically advisable methods of medication taking, such as only taking medication at certain times or moving to intermittent use or even non compliance as a positive attempt regaining control (Britten et al 2010; Pound et al 2005; Cooper et al, 2007). Worryingly Read (2005), in a mixed methods study, found that service users would

often not inform or even consult practitioners with the serious decision to come off psychiatric drugs, highlighting a lack of trust. Participants also described not receiving adequate advice or information, indicating a lack of open discussion and dialogue.

It may be internet forums could offer increased opportunity for exchange of personal experiences and other knowledge sources in the wider community and it is likely that service users may have sophisticated and nuanced understandings of the use and effects of psychiatric medication (Pestello and Davis-Berman, 2008). In addition a growing number of community groups have been organised in recent years in different parts of the UK, with a focus on psychiatric medication and a sharing of experiences and knowledge (Nottingham Mind Medication Group; Leicester Living with Psychiatric Medication Group, both cited in Coles et al, 2013). As such, knowledge and expertise about psychiatric medication may be extensive but it may not necessarily form part of the formal consultation about psychiatric medication with clinicians.

2.7.1. Summary

In summary, the research exploring MHSUs views towards decision making shows a general increased desire for involvement. However the decision making process is complex, multifaceted and a protracted process of trial and error (Davidson, Miller and Flanagan, 2008). The values of choice, self determination and empowerment are central to recovery (Deegan and Drake, 2006). The key element for service users would appear to maintain a trusting, honest and open therapeutic relationship, where service users' expertise (both from previous experiences of using medication, knowledge gained through difference sources, and individual preferences) is valued in an encounter, enabling increased levels and experiences of being in, or taking back control. Nevertheless, there remains a lack of detailed studies exploring preferences and experiences of psychiatric medication management and further research is needed.

2.8. Practitioner views and experiences

According to the review of literature conducted by Patel (2008) there is a cautious willingness towards concepts such as shared decision making in mental health treatment decision making. In particular, SDM is seen by practitioners as an important tool for service users to gain increased control, supporting recovery oriented practice and person

centred care (Mahone et al, 2011). However, there is more focus within this literature on the barriers to implementation of SDM. Practitioners have expressed barriers including:

- Competence of SUs to participate
- A preference for practitioners to rely on intuition regarding patient interest in SDM
- Fears around impact on medication use/uptake
- Time
- Communication and relationships with other team members
- Focus on risk avoidance management in MH service delivery, at the expense of positive risk taking.
- Coercive practice and enforced compliance

(Gravel, 2008; Legare et al 2008; Patel et al 2008; Torrey and Drake, 2010).

Interestingly, some of these concerns may not have a strong foundation. For example, implementing SDM may not automatically increase consultation time (Loh et al, 2007b).

Seale et al (2006) conducted 21 qualitative interviews exploring decision making for medication management with consultant psychiatrists working in adult mental health services in the UK. They concluded that the psychiatrists had a genuine commitment to democratic and shared decision making. A number of approaches and practical strategies were referred to by psychiatrists to promote shared decision making including: listening to people's views about their current situation and experiences of medication use, showing empathy and understanding, having respect, using language thoughtfully, tolerating conflict and managing hostility. Once again the importance of establishing a relationship over a long period of time was mentioned.

However a number of obstacles particular to psychiatry appeared to prevent opportunities for the psychiatrist achieving a fully concordant relationship with service users. At the fore front of these was a judgement of competence or insight. This is at odds then with research which demonstrates that consumers of mental health services are generally capable of making decisions related to their care, despite decisional impairments which are characteristic of many chronic mental health disorders (Loh, 2007a). In the Seale et al study (2006) psychiatrists acknowledged that, at times, more persuasive and directive strategies are employed and sometimes deception is necessary.

However the psychiatrists interviewed were very aware of the potential damage using coercive measures had on the longer term therapeutic alliance with the service user and

tried to adopt strategies to limit this damage. Alongside this, there was also doubt that the service user was being fully honest and open. The psychiatrists interviewed often referred to adopting strategies to overcome this including persuasion, bargaining and deception, thus also indicating a lack of trust in the encounter. A key dilemma for psychiatrists was, on the one hand, psychiatrists strongly valued and believed in medication treatment as helpful, yet on the other hand, they were worried about the impact on non adherence, if all adverse side effects were presented. The heavy reliance of psychiatrists on medication to control symptoms may therefore impede psychiatrists from fully engaging in a collaborative decision making. As such these results point to the fact that the psychiatric encounter is unbalanced in terms of powers and fits with research which shows that service users often will present a false picture of compliance (Britten et al, 2010), thereby allowing the psychiatrist to continue to believe the decision was a concordant one.

In McCloughlen et al's (2011) study of psychiatric nurse and service users' views and experiences of collaborative decision making, a similar picture emerges. This Australian focus group study found that while both service users and nurses strongly valued a collaborative relationship, the experiences of collaboration between the groups was inconsistent. Many of the nurses felt they employed collaborative decision making with service users. Nurses referred to perceived barriers associated with multi disciplinary working resulting in a lack of autonomy to make decisions, thereby influencing the ability to form a fully collaborative relationship with service users. The service users, however, did not express such an opinion, yet only half felt that they had a collaborative relationship with the nurse. Instead the strong theme for service users was concerns that their 'voice' was not heard in discussions and personal experiential understanding was not valued in the decision making process. Notwithstanding this, often service users would continue to portray a false picture of compliance in order to maintain the ongoing relationship with the nurse and therefore allow for a facade of shared decision making to be built and maintained (also see Barry et al, 2007).

2.8.1. Summary

In summary, research exploring practitioner's perspectives of SDM in psychiatry is limited. Research suggests that practitioners have a strong commitment to the values of shared decision making and a democratic approach to decision making in psychiatry, but that this may not implemented in practice. The systematic power imbalances present in the

psychiatric system¹³ are perceived as key barriers in being able to achieve an equal partnership in psychiatric medication management encounters.

2.9. Research exploring current decision making practice in mental health

Very little research has explored how decisions are currently being made in psychiatric medication management. Most of this research has either focused on examining the extent to which SDM is occurring in practice or more generally, the degree to which a therapeutic relationship is established, using quantitative tools of measurement, such as; the Observing Service User Involvement in Treatment Choices Instrument (OPTION) scale (Elwyn et al, 2003;2005) and the Scale To Assess the Therapeutic Relationship in community mentalhealth care (STAR) scales (McGuire et al, 2007).

The research which has explored the model of SDM in psychiatric practice does not paint a particularly positive picture. Loh et al (2007a) found that decision making is only happening, at best, at the first stage of information exchange (as defined by the Charles, Gafni and Whelan model, 1997, p. 10). In addition, a recent study conducted in a community mental health team found that while 61 % of recorded consultations reflected the practitioner perspective, less than 10% reflected both the service user and practitioner perspective (Matthias et al, 2012).

Goosensen (2007), on the other hand, offers on the face of it, a slightly more positive picture of SDM practice within mental health services, in a multi site European study. Using the OPTION scale to assess SDM in psychiatric consultations during outpatient clinics, the results showed that observers rated some items highly (see table 2). For example, providing opportunity to ask questions and indicating the need for a decision was highly rated. However clinicians did not regularly explore service users' expectations and concerns. In addition, service user preferences towards involvement were not requested. Thus, whilst on the face of it these results may suggest a more positive picture towards the practice of SDM, the key elements of SDM (see S. 2.4) of placing an equal value on different types of knowledge (through the genuine exploration of patients expectations and concerns) was not observed in this study.

¹³ See chapter three for further discussion

HIGH scoring items from OPTION scale	Mean observed score (0-4)	LOW scoring items from OPTION scale	Mean observed score (0-4)
Clinician offers patient explicit opportunities to ask questions	3.44	Clinician explores patient expectations	1.30
Clinician indicates need for a decision making stage	2.87	Clinician explores patient concerns	1.18
		Clinician asks for preferred level of involvement in decision	0.20
		Clinicians ask for preferred approach to receiving information	0.10

Table 2: Findings taken from Goosensen (2007) indicating high and low observed scores from OPTION scale

These pessimistic findings have been replicated in other recent studies (e.g. Goss et al 2008; McCabe et al, 2013). Indeed the study by McCabe et al (2013), which videotaped 72 meetings with psychiatrists, found lower observed levels of involvement (OPTION scale) than found in both the Goss et al (2008) or Goosensen study (2007). However, one explanation proposed by McCabe et al (2013) was that decisions were often made over multiple meetings. This is perhaps is not compatible with the OPTION scale's focus on a single decision point¹⁴. In this study, psychiatrist characteristics were related to the level of involvement observed, with, in particular, female clinicians showing increased SDM behaviours.

Findings from qualitative studies also suggest that SDM is not fully operational in practice. Indeed, in an intervention study by Rogers et al (2003), which explored the views and experiences of people who had a diagnosis of schizophrenia, the findings are stark. Two interventions were investigated: one being a traditional paternalistic approach to medication management, the other employing shared decision making principles. The

¹⁴ The OPTION scale fits with transactional models of SDM, which may be less applicable for psychiatric medication management. See S. 2.5 for further discussion.

findings showed that both groups experienced positive responses from service users, in comparison to their prior routine experience with services. This was mainly due to the increased communication with practitioners during both groups. Thus, during routine practice, service users received little information or instruction about the nature or effects of their medication and that, at least in this study, psychiatric medication management does not attend to core principles of communication and patient centeredness.

Although this research investigates how practice compares to the ideal models of decision making and collaboration discussed in the previous section, it does not seek to explore how circumstances relate to strategies employed by practitioners and service users, in psychiatric medication management. In addition these studies provide limited insight about how decisions concerning psychiatric medication are negotiated in practice.

Previous research in this area indicates that degrees of pressure are applied by psychiatrists in decision making encounters (Lidz et al., 1993; Szmukler and Applebaum, 2001), with persuasion being, by far, the most prevalent techniques employed by psychiatrists (that is, stating a preference or invoking expertise). This is compounded by a fear of more explicit coercion and compulsion to adhere to treatment. It is thought that more directive but subtle pressure exerted in outpatient clinics has a negative impact on service users fully engaging with mental health services or achieving concordance (Day et al, 2005). In a conversation analytical (CA) study, McCabe et al (2002) found that psychiatrists used various interactional strategies to both resist engagement and avoid conflict surrounding patients' concerns or questions about their experiences of hearing voices (McCabe et al., 2002). Seale et al (2007) found a similar pattern in their analysis of psychiatric medication review meetings. Here, in response to service user concerns about sedation and mental clouding (a side effect associated with anti psychotic medication) psychiatrists commonly either; construed the symptoms as positive (e.g. helpful for sleep); avoided an open discussion about the concerns (e.g. offered no response) or; questioned the validity of the service user's interpretations (e.g. suggesting concerns may be unrelated to the anti psychotic medication). These results suggest a range of strategies employed by psychiatrists to guide conversations concerning particular side effects, thereby avoiding overt conflict in the encounter concerning psychiatric medication, and encouraging adherence. This pattern was also highlighted in a study by Mendel et al (2009). This experimental study found psychiatrists more likely to focus on medication benefits rather than risks when presenting information about anti psychotics to service users, thereby guiding the conversation towards adherence.

However, and interestingly, in a recent re analysis of the same 92 recorded meetings referred to in the Seale et al (2007) study above, it was found that when non adherence is disclosed by service users, it is often responded to positively by psychiatrists and results in an open dialogue about medication choices (Quirk et al, 2012). A spectrum of pressure has been proposed to account for the diversity in the encounters (Quirk et al 2012; Quirk, 2007). This analysis highlights that whilst a roughly equal number of decisions regarding psychiatric medication were initiated by the service user, as by the psychiatrist, how 'shared' the dialogues were in practice, differed. As shown in Figure 4, the conversation analysis findings suggested a variety of different ways of reaching a decision. This study found that consultations were often highly negotiated, with little evidence of direct coercion or compulsion by the psychiatrist. However the manner of the conversations were such that the service user may have felt they had very little influence over the outcome and when looking in detail, shared decision making as an ideal was not conformed to.

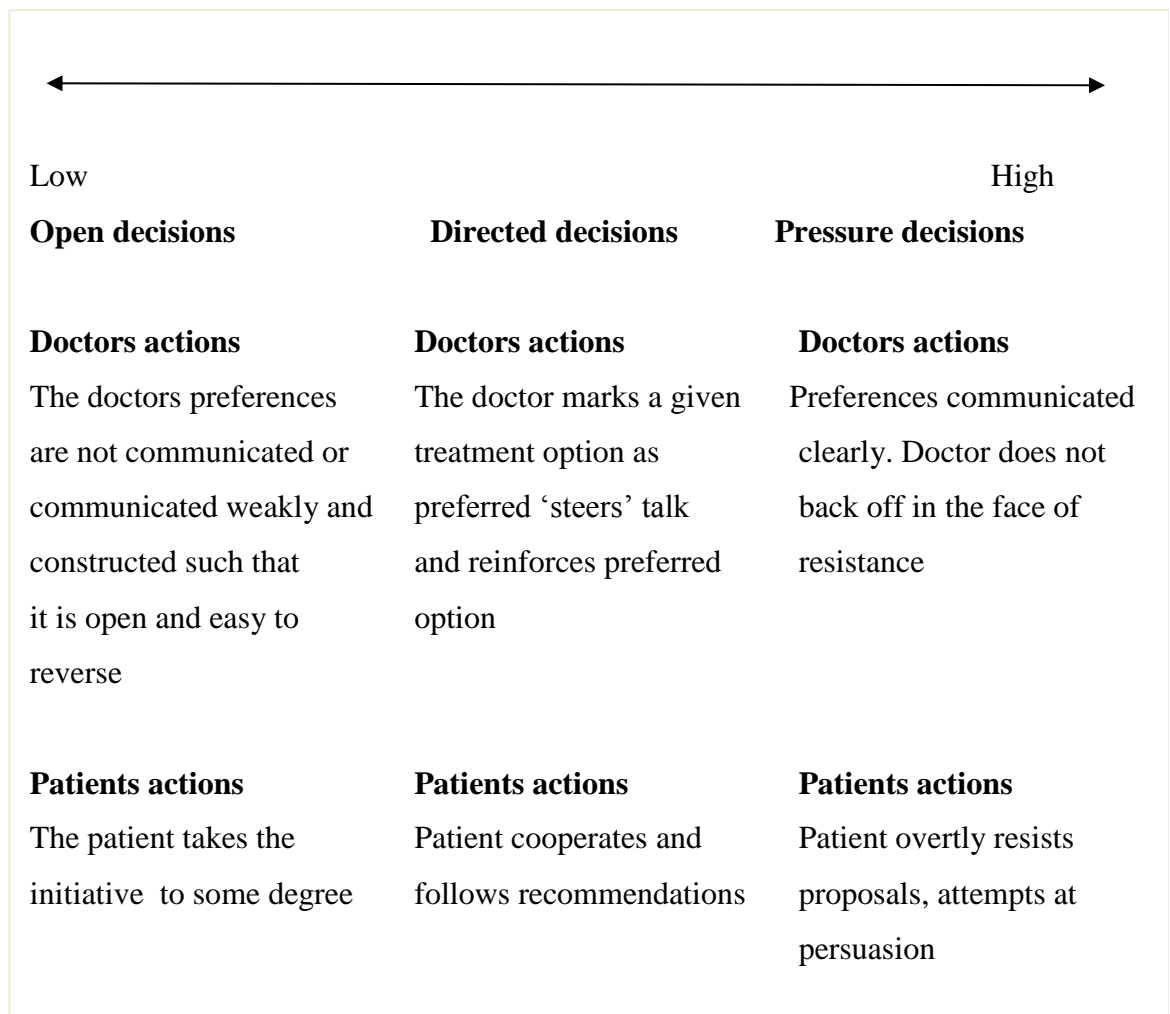


Figure 4. Types of negotiated decisions positioned on a spectrum of pressure. Abbreviated from Quirk (2007, p.174)

Thus for a high proportion of meetings analysed, while medication options and relevant information about side effects is presented, the decision is nevertheless directed by the psychiatrist, through the use of conversational strategies (e.g. use of the caveat 'but' to rule out options) thereby encouraging selection of the 'preferred' option. Quirk (2007) notes, however, that at no point does the service user suggest that the psychiatrist's actions are a form of manipulation or are unwanted by the service user. According to Quirk (2007) this is.

... a negotiated decision in which the participants are 'letting the patients have it the doctors way' – a meaning produced collaboratively, by the diplomacy of the consultant and absence of resistance by the patient...

(ibid, p.164)

Such an approach, as discussed previously, may allow the psychiatrist to genuinely value a collaborative approach and maintain the self image of working according to SDM ideals, but in practice there may be a restricted freedom of choice over the decision, as experienced by service users.

One other finding of note from this extensive work is the tendency for psychiatrists to 'back off' when resistance or pressure is applied by the service user. Avoidance of conflict and the importance of maintaining the ongoing therapeutic relationship was highlighted in this analysis. However, whilst making an important contribution to understanding the processes of decision making about psychiatric medication, this study ignored situations of tacit non or false compliance, as mentioned above¹⁵, which is one of the strategies open to patients who disagree with their prescriber, but choose not to communicate openly about this. This may be particularly poignant to community based psychiatric medication management, where non adherence rates are high (see context chapter).

2.9.1 Summary

The research exploring SDM in practice in psychiatry has mainly used quantitative tools for observational measurement and suggests that SDM is not fully being employed in practice. The research which has explored the behaviours and strategies employed by service users and psychiatrists suggests that a spectrum of pressure exists within a typical consultation meeting, such that meetings, whilst not being directly coerced, vary in the

¹⁵ See Seale et al, 2006; Britten et al, 2010

level of information service users receive or in the amount of freedom to decide the service user feels they have.

2.10. Concluding remarks and areas for further exploration

Shared decision making is proposed to be the ideal model of practice in psychiatric medication management and is regarded as a tool for recovery. The model of SDM and research exploring its utility however has originated in other fields of medicine and conceptual understanding of what SDM means is not fully agreed upon. Little research has explored the views, preferences and experiences of service users and practitioners towards making decisions about psychiatric medication or explored what factors are important towards achieving shared decision making in practice. The research suggests that on the face of it, key stakeholders endorse shared decision making as an ideal approach to making decisions, however certain barriers and contextual factors, specific to psychiatric medication management emerge. A fuller conceptualisation of shared decision making for mental health medication management is needed.

Even less research has explored the current practice of decision making in medication management in mental health. SDM does not appear to be fully operational in practice and a level of pressure is applied by psychiatrists (if not practitioners more generally) and, to a certain extent by service users, when negotiating decisions in this area. The inherent power imbalances present in the psychiatric system results in a specific dynamic of practice for decision making in mental health. Both practitioners and service users claim to value the ideals of *a meeting between experts* and conform to the idea of differing knowledge having equality, yet the differing power imbalances and structural components in the mental health system appear to be a barrier to achieving these ends. The subsequent chapter explores these issues in more depth, presenting the theoretical underpinnings and conceptual framework for the thesis. The theoretical construct of power is considered and influential theories evaluated, focussing on their applicability to the context of psychiatric medication management.

2.11. Research Questions

This thesis explores the views and experiences of both service users and practitioners, allowing for a more comprehensive understanding of the everyday realities of shared decision making for psychiatric medication management. Barriers to and enablers of SDM

for psychiatric medication are investigated, as a more sophisticated and multi-faceted construction of shared decision making for psychiatric medication management is sought for.

There are two overarching research questions for this thesis:

What are key stakeholder views about shared decision making for psychiatric medication management?

How are decisions about psychiatric medication made in practice?

Within these overarching research questions, some key research themes are identified:

- The enablers of and barriers to shared decision making for psychiatric medication management.
- Current medication management practice in community-based mental health services
- Similarities and differences in how SDM is conceptualised between stakeholder groups
- Acknowledgement of a need for change, making recommendations for practice based on the findings.

Chapter Three. Theoretical underpinnings and conceptual framework

Chapter Outline.

This chapter explores the theoretical construct of power in the context of psychiatric medication management practice. It considers influential theories of relevance to the thesis. Drawing on this literature, the chapter concludes with a conceptual framework for psychiatric medication management.

3.1. The concept of power and its relevance to shared decision making in psychiatric medication management

The review of the literature and research context chapter points strikingly towards the need to explore the concept of power. This chapter describes some theories of note in this huge area of literature, pointing to relevant aspects to consider for medication management practice in contemporary mental health services. This does not offer the reader a critical evaluation or thorough examination of the power literature. It does not even offer a whistle stop tour. Rather, it reveals the different forms of power that may be applicable to consider when exploring SDM, as well as presenting useful theoretical representations of this construct in order to provide a sense of structure and meaning relevant for considering SDM in psychiatric medication management.

Weber (1864-1920) conceptualised power as 'power over' - as something that can be done unto someone, with person A having *power over* person B. In the context of mental health, it has been suggested that those who possess power (i.e. the professionals and particularly the prescribers / psychiatrists) would need to surrender or hand over some of their own power if shared decision making is to take place and as such this is '*a reason to resist genuine service user empowerment*' (Masterson and Owen, 2006, p.21). Within this form of power, professional power and the understanding that certain types of knowledge have more weight is still applicable, suggesting that for this form of power, expertise can only be challenged with expertise (Gaventa, 2008). As such there is an overt conflict, but domination, of the powerful (mental health professionals) over the powerless (service users) with ideas such as compliance to medication regimes being particularly relevant. This form of power is often recognised as overly negative, and as having associations with

terms such as coercion (Veneklasen and Miller, 2002). Studies of the asymmetrical psychiatric encounter and the role of status and authority on the dynamic of decisions about psychiatric medication fit with these conceptualisations of power, focussing on how power claiming strategies are employed, and how adherence or compliance to medication routines is encouraged by prescribers¹⁶.

Many modern theorists, however, look beyond this simplistic or hierarchical picture of how power imbalances are played out in the context of the mental health system. The important work of Lukes is widely regarded and has received some attention for its applicability in considering the mental health context (Brosnan, 2012; Masterson and Owen, 2006).

Lukes proposed that the Weberian or 'behaviourist models' of power are inadequate because:

....although A may exercise power over B by getting him to do what he does not want to do, he may also exercise power by determining his very wants.

(Lukes, 2005, p.107)

Instead Lukes has proposed a three dimensional view of power. The first dimension is comparable to the Weberian form described above, that of *power over* and associated with scenarios of conflict where one party has power over another. However in the second and third faces of power, more covert forms of power are described. The second face, also described as 'non decision making', is power that is exercised by the powerful (the professionals or prescribers), but by controlling what is on the agenda for discussion, or more specifically, by controlling which particular options are open for discussion. So, in the case of psychiatric medication management, this may involve which types of medication are described by professionals as options, or whether non medication alternatives are in fact considered at all. The central issue of side effects is also important to consider at this level of power. Side effects and the risk benefit profile of different psychotropic medications are central to the balanced weighing up of the pros and cons of a shared decision concerning psychiatric medication. The presentation of the side effects is, however, in the hands of the psychiatrist, whose competing interests and limited time available, pose a challenge for the full disclosure of information needed for a fully shared dialogue. Whilst the internet and other 'open access' forms of knowledge, may assist the

¹⁶ See chapter eight for more details

full disclosure of information to mental health service users at this level, this remains inconsistent, potentially misleading and influenced by structural factors such as education levels, class and age (Preston, 2013). Other factors may also be important to consider at this level of power, such as expense of medication and direct marketing incentives, influencing which options are presented in the psychiatric medication encounter.

However, this second dimension of power still maintains the idea that the exercise of power involves conflict between parties, or rather between the powerful (prescribers) and powerless (mental health service users) over recognised areas of conflict. Lukes' defining contribution to the literature was to explore a third dimension of power, which challenges this, instead suggesting the most insidious form of power is that which prevents conflict from emerging in the first place. Thereby linking power with ideas associated with the work of Friere and others; exploring power via wider repressive cultures and internalised or self stigma. At this dimension of power, identities and roles are manipulated so that certain groups do not question and accept certain situations without conflict. This is highly poignant to much of the critical psychiatry literature where it has been argued that this form of power is present in the dominating bio medical model of psychiatry. In particular for psychiatric medication management a dominating bio medical model may hinder the recovery ideals of the service user taking back control and empowerment, via the mechanism of distancing the value of experiential knowledge (Masterson and Owen, 2006).

In summary, the three dimensional view of power presented briefly above is a useful way of exploring how power is played out in a psychiatric encounter, both overtly through authority and power over in decisions about psychiatric medication, but also and perhaps more importantly how more covert forms of power represent themselves in the medication management encounter - through deciding which options are discussed (the second dimension of power) and by considering what is deemed socially acceptable as relevant knowledge for the decision in the first place (the third dimension of power). This is relevant in considerations concerning equality of knowledge, a meaningful weighing up of options; and experiences of control by the service user.

Taken together in the context of psychiatric medication management, 'power', as an obstacle to the defining aspects of SDM, is an important theoretical construct to incorporate.

There are strong links with Lukes' third dimension of power and Foucauldian approaches to power, which, in addition, emphasise the positive aspects of power in social relations. Foucault's widely quoted phrase '*knowledge is power*', is often misinterpreted as meaning how knowledge can be used as a form of power. However, this actually refers to how power is constructed, and subsequently maintained through discourses and institutional practices that frame action and govern what is seen as possible. For Foucault there wasn't a distinction between knowledge and power, both being inherent upon social relations, affecting every person in every role, both the service user and professional alike. Thus, whilst linked to Lukes' third face of power, it also refers to positive aspects of power, emphasising that within institutions, such as mental health service delivery, hierarchies of knowledge are created which place certain people in certain roles (i.e. psychiatrists and/or prescribers) as having more control over decisions concerning psychiatric medication. Unlike Lukes, however, power for Foucault was not seen as something *possessed* by those who exercise it. Instead, power is a strategy and network, and mental health professionals are just as much a part of this network of social relations, as service users. Thus, for Foucault, power is exercised by actions, as oppose to being exercised by a particular person in a certain position or role (Couzens - Hoy, 1986). Applying this notion of power in the context of psychiatric medication management, the meeting itself is of importance to consider, with power being exercised through use of strategies employed by all participants as part of the wider social relations of the meeting. Doctor - patient asymmetry and patterns of social relations may be important to consider at this level, then. Indeed, Foucault's work has been used extensively in areas of health and medicine, exploring both the caring profession and traditional doctor patient studies, focussing on how medicalised forms of knowledge impact on identity and behaviour in medical encounters (Petersen, 2010).

Medicalised discourses and diagnosis are important hierarchies of knowledge at this level and are played out through the pattern of social interaction in the psychiatric medication encounters. A contemporary example is illustrated by the recent controversy following the release of the new Diagnostic and Statistical Manual (DSM 5) in 2013. Its release was associated with a much public debate and discussion. In particular, new diagnostic categories incorporated into the DSM 5 highlight the increasing medicalisation and, further pathologising of emotions and behaviours (Jacob et al 2013; DCP, 2012). This pathologisation and the increasing trend towards creation of new distinctions between what is seen as normal and abnormal is proposed to be a form of power and control, via the mechanism of voluntary compliance (Foucault, 2005). As such, societal expectations and the dominance of medicalised perspectives of emotions, behaviour and distress may

be an important structural factor in the psychiatric medication management encounter, resulting in the less powerful enforcing the aims of the powerful, through self surveillance.

.....there is no need for arms ,physical violence, material constraints. Just a gaze. An inspecting gaze, which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over and against himself.

(Foucault, 1980, p. 155)

Studies which have adopted foucauldian framework in their analyses have particularly emphasised how information presentation is framed and how documentation is used to create a consensus. This links again to the ideas of avoiding overt conflict in the encounter by the creation of subtle constructions of argument about psychiatric medication, further impacting on the shared decision making process.

However, one of the main criticisms to the foucauldian approach to power is, whilst seen as a form of critical theory, it does not construct a new systematic set of principles of power, but instead reconciles to criticising other theories. His work has been criticised as overly fatalistic, not encompassing the idea of universal progress. However, Foucault maintained his position that emancipation or empowerment was still possible, if taken at the local level, in terms of pockets of resistance to exercises of power.

Another important aspect of power relevant to psychiatric medication management encounters, but paid little attention by Foucault, is the influence of industry and wider economic structures in shaping discourse. Petersen (2012) argues *neo liberalism is a manifestation of late, free market capitalism and we need to better understand how the particular forms of governance associated with contemporary health and medicine and healthcare reflect and are shaped by the dynamics of the political economy* (ibid: p,17). For example, as applied to psychiatric medication management, Rose (2003) critically explores the influence of the pharmaceutical industry (see Chapter one).

Lukes' 'three faces of power', have however also received criticism. For some, it ignores other types of power such as *power with*, *power to* and *power within*, associated with empowerment and transformational change. *Power with* is seen as achievable through working together in groups, for advocacy and change. *Power to* act relates to this but also links to ideas of agency and autonomy (or *power within*). These other forms of power are largely ignored by Lukes, but it is suggested, remain highly relevant within the psychiatric encounter theories (VeneKlasen and Miller, 2002).

There is also a body of research which has explored the importance of acknowledging the resistance and strategies employed by the less powerful in the encounter. The importance of exploring *false compliance* to medication regimes is particularly poignant to the medication management encounter in mental health. Scott (1990) explores the importance of the 'hidden transcript of the subordinate' as a way of explaining the phenomenon of passive resistance. Here, the main premise is that the discourse of a *subordinate* group is vastly different when in the presence of a dominant group as compared to when in the company of peers. This is highly relevant to considering psychiatric medication management practice. That is, the idea of 'acting' or presenting a false picture of compliance in order to avoid confrontation and conflict in the medication management encounter. However active non compliance strategies are not seen as the only subversive form of power.

..the conflict will (also) accordingly take a dialogic form in which the language of the dialogue will invariably borrow heavily from the terms of the dominant ideology prevailing in the public transcript.....We may consider the dominant discourse as a plastic idiom or dialect that is capable of carrying an enormous variety of meanings, including those that are subversive of their use as intended by the dominant.

(Scott, 1990, p. 102).

Thus, not only are the covert or passive forms of power associated with subversive actions, such as not taking a prescribed medication and active non compliance, but also within dialogue itself, through redefining the use of the dominant discourse. In other words, impacting on how mental illness is conceptualised and what are deemed the social norms of mental health prescribing practice, through the use of using dominant discourse (e.g. language and norms associated with the dominant medical model in psychiatry).

On another level, it is important to recognise movement, change and resistance at a wider cultural and system level of understanding. Over the last half a century there has been significant critique of the bio medical model in psychiatry, labelled as oppressive and an insidious component of contemporary mental health services. Movements of resistance have emerged over the same time period. For example, Crossley (2005), in a sociological examination of the mental health field from 1950 - 2000 identifies five distinct but inter related social movements over this period:

- 1) Mental hygiene movement
- 2) Civil rights movement
- 3) Anti Psychiatry movement

4) User / survivor movement

5) has no label but comprises of a movement where families / carer are critical of 2,3 and 4 and support diagnoses.

Having considered some of these additional complexities and avenues that are relevant to power in medication management practice, we can now return to Lukes' three dimensional model of power. One of the seen benefits of this model is its simplicity in presentation of the ideas surrounding power. Gaventa (2006;2008) expanded on Lukes' work, to make it more applicable to ideas of encouraging empowerment and change in a development context. Here, Gaventa's aim was to make more explicit where power can be acted upon (or as Gaventa calls them - engagement spaces) within a participatory framework to encourage change in organisations. By making these 'spaces' more explicit, challenges to these barriers may emerge, such as being able to prevent certain issues from arising, as well as the increased mobilisation of less powerful or excluded voices / knowledge. Gaventa represented these ideas using a power cube which he defined as *a framework for analysing spaces, places and forms of power and their inter relationship* (Gaventa, 2006, p.26).

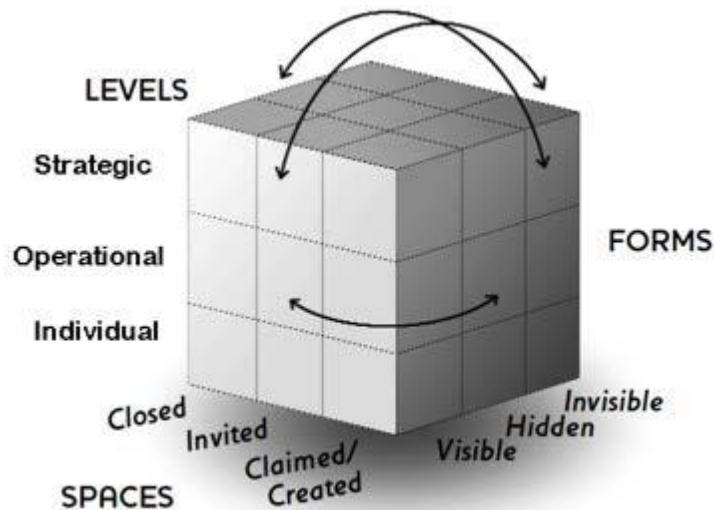


Figure 5. Gaventa's power cube, levels, spaces, and forms of power operational in mental health service-user involvement. Adapted by Brosnan, 2012, p. 14.

Brosnan (2012) has adopted this framework (see Figure 5 above) to explore user involvement in mental health services in Ireland, suggesting it is both applicable to the mental health context and useful for making more explicit the role of power as an obstacle to user involvement in mental health. Lukes' representation of both overt and more

hidden forms of powers are presented as layers to the cube, occurring on different planes; the strategic, operational and individual levels. Ideas of creating new spaces within these planes is also explored: closed, invited, and created spaces, to emphasise how change may happen on the different planes. Finally by presenting the layers and spaces as a rubix cube, complexity is emphasised, presenting numerous combinations of forms, levels and spaces.

Whilst useful, this representation does present a rather static picture of power. Although it enables the appreciation of how and where strategies can be employed to 'tackle' power in the context of psychiatric services, it does not really talk about the changing or dynamic context of power or of the strategies already employed by the less powerful in the context of a dynamic changing social relationships, as alluded to in the below quote:

Power can be defined as the degree of control over material, human intellectual and financial resources by different sections of society. The control of these resources becomes a source of individual and social power. Power is dynamic and in relationships, rather than absolute...,but neither power, ideology, not the state are static or monolithic. There is a continuous process of resistance and challenge by the less powerful and marginalised sections of society, resulting in various degrees of change in the structure of power. When these challenges become strong and extensive enough, they can result in the total transformation of a power structure.

(Veneklasen and Miller, 2002, p. 41)

In this quote the dynamic nature of power is emphasised, with the idea of continual change and review being important to the concept of power. This idea of power and its impact on systems and change is explored in depth by Clegg (1989) who discusses *circuits of power*, thereby moving the concepts of power towards a more dynamic idea of power, than those presented by Lukes or Gaventa.

3.2. Structure and agency in medication management practice

At this point, it is also useful to consider the concepts of structure and agency in psychiatric medication management practice. The definitions of structure and agency are contested and depend on the school of thought. The characteristics of structures vary in the following ways:

- In character (for example, in purpose, organisation, the role informal networks and the existence of a sub culture)
- Scope (local - global)

- Dynamism (stable - unstable)
- Durability (long - short duration)

(Sewell, 1992)

The above characteristics allow for an appreciation of the overlapping, diverse and intersecting aspects of structure, which is particularly relevant for SDM in psychiatric medication management. Adopting this perspective, differing, overlapping and potentially conflicting structures are acknowledged in modern mental health medication practice. In other words a multiplicity of structures are present and acknowledged. The historical and contextual factors of contemporary mental health services have been briefly explored in Chapter one. For instance, diagnosis and the medicalisation of mental illness are dominating structures, often associated with concerns over a depersonalisation of experience and creating stigma. This has the potential to be a significant challenge to achieving the ideals of shared decision making and is therefore is an important structural factor to consider for psychiatric medication management. However this is intersected by the recovery model, which is mainstream in modern mental health policy¹⁷, and the broader historical movements linked to this (eg. the survivor movement, the social model of disability, and growth in neoliberalism in health care provision) . These structural components may be associated with increased personal control, provision of choice and empowerment for mental health service users, bringing service user perspectives more to the fore and encouraging increased personalisation of care, and a move away from a deficits based perspective. Linked to this, positive psychology has also emerged as an influential knowledge base in the last couple of decades, emphasising the importance of wellbeing and a focus on strengths as oppose to treatment of illness, in delivery of mental health services (Slade, 2010). Indeed the WHO declaration of mental health also reflects these recent developments in mental health structures:

'a state of well being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community'

(WHO, 2004)

This definition also emphasises the growing appreciation of meaningful relationships, social inclusion and wider communities as essential components for mental health. Slade (2010) goes on to suggest that mental health professionals will need:

¹⁷ See Chapter one for further details

'to focus on improving social inclusion, becoming social activists who challenge stigma and discrimination, and promoting societal wellbeing [and this] may need to become the norm rather than the exception for mental health professionals in the 21st Century.'

(ibid, p. 2)

These structural components and their intersection in modern mental health system is highly relevant to consider for shared decision making in psychiatric medication management. This intersection of structures is discussed in Archer's (1995; 2003; 2012) seminal work and her theory of morphogenetic cycles. In this work, Archer explores the variety and dynamic societies of late modernism.

... structure and culture have each become morphogenetic and are coming to stand in a relationship of positive reinforcement towards one another. The new generative mechanism entailed by this is for variety to produce still more variety because, in pure form, nothing restrains it (such as defensive attachment to previous quasi traditional interests and ideas or adherence to prior forms of routine action). Even more importantly, in pure form, it can develop because the very novelty of new variety means that no group has commandeered it an acquired vested interests in it. Indeed the rapidity of change means that the very notion of vested interests will become outdated if and when morphogenesis becomes truly unbound'.

(Archer, 2012, p.31).

This offers a dynamic perspective on structure, but one that reflects the diversity, as well as representing the uncertainty, change and movement of structures in the mental health system. Although power or social capital may remain, the links are less direct and according to Archer (2012) are often via indirect routes, such as the transmission of confidence in being able to pursue opportunities. Applying this to psychiatric medication management this suggests that whilst vested interests and power remains, there are a multiplicity of structures which potentially enables greater flexibility in how people (individually or as a groups) move forward and take action (agency).

There is a lot of debate in the literature as to how agency and structure interacts. On the one side, theorists propose a fatalistic stance of agency, such as Bourdieu's *habitus*, where structure is all encompassing and mutually reproducing. For example, in Scrambler's exploration of the Bourdieu's *habitus* for decision making in healthcare:

...choices may be rendered meaningless to those who lack the resources to make a meaningful choice. This has particular resonance if one considers the changes to the

national health serviceIn the field of health, habitus has been characterised as one of passivity and compliance. The power structure of the field within which health, habitus is enacted is one in which medical and allied professionals take the position of power and control the interactions. Thus the passivity is structural.

(Scrambler, 2012, pp.75-76)

Whilst the issues of passivity are highly relevant to mental health medication management, as suggested, this stance potentially ignores the dynamic and intersecting aspects of structure and the potential for agency to be brought further to the fore. This position therefore '*assumes a far too rigid causal determination in social life*' (Sewell, 1992, p.2) where agency has little influence. Thus this is at odds with the dynamic picture of structure presented above.

At the other end of the spectrum, theorists propose agency only is viewed in relation to an individual's decision making process. This, again, is less relevant to psychiatric medication management practice, where the historical, economic, and social context are all highly poignant and strongly influence wider psychiatric medication management practice.

Instead, in the middling position endorsed by theorists such as Giddens (1979) and Archer (1995), structure and agency are seen as interacting in determining psychiatric medication management practice. In other words, *agency is necessarily structured but not structurally determined* (Scrambler, 2012, p.131). This is a useful position to adopt in considering psychiatric medication management practice.

According to this perspective:

'to be an agent means to be capable of exerting some degree of control over the social relations in which one is enmeshed, which in turn implies the ability to transform those social relations to some degree'

(Sewell, 1992, p.20)

Archer (2012) proposes that there are four modes of agency possible. These are; communicative reflexivity (*internal conversations need to be confirmed and completed by others*); autonomous reflexivity (*internal conversations are self contained, leading to action*); meta reflexivity (*internal conversations critically evaluate previous inner dialogues and are critical about effective action in society*) and finally fractured reflexivity (*internal conversation cannot lead to purposeful action, but intensify distress and disorientation*). In Archer's model, (Archer, 1995), the interaction and change between structure and agency is a process through time as a cycle (called the morphogenetic cycle), consisting of societal

interactions and structural elaborations (where conflict and negotiation between societal groups further impacts structural change).

3.3. Conceptual framework

Reflecting on this literature, Figure 6 presents the conceptual framework for the thesis, highlighting levels or layers of analysis for exploring SDM in psychiatric medication management practice. This diagram has the added aim of making more explicit the notion of power as a core concept for shared decision making, and emphasising the dynamic nature of the decision making process. Whilst it is highly useful to consider different dimensions of power as well as different levels of analysis, as shown by Gaventa's power cube, this diagram aims to also emphasise movement, resistance and in general, present a dynamic representation of medication management decision making, with the relationship between the layers in flux.

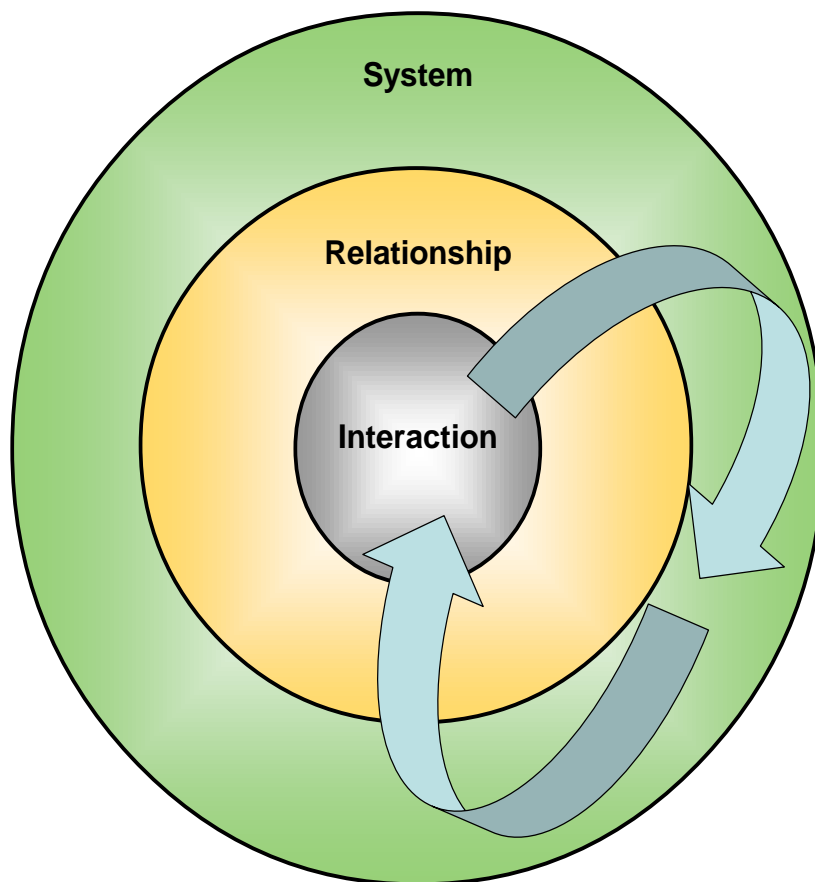


Figure 6. Conceptual framework: Levels of analysis for psychiatric medication management practice.

Different levels of analysis are presented in an onion diagram to emphasise that power exists on different planes, both at the system (or macro) level, the relationship level, and the interaction (or micro) level. The diagram illustrates that power is embedded within each of these levels. For example, at the system level the dominant ideology of the bio medical model is present, as are other forms of established norms, such as Aescuplian power (or the power to heal) applicable in all medical encounters. However, other structural components are also embedded at this level, including amongst others; the personal recovery model with its roots in the survivor movement, contemporary shifts towards neo liberalism and a rhetoric of choice, changes in expectation towards increased patient involvement in decision making, and management of risk and the legal framework within which mental health services operate. These embedded structures directly impact on the inner layers. In fact the relationship and interaction levels are seen to sit within the outer system circle, presented as an onion based diagram. This represents ideas from Foucault, and Lukes' 3rd face of power, i.e. that power is ever present and sits within wider structures and discourses, impacting covertly what is possible at the interaction level, where decisions about psychiatric medication occur. At the interaction level, SDM may be impeded both overtly through authority and 'power over' in decisions about psychiatric medication, but also through deciding which options are discussed in the first place (the second face of power) and by considering what is deemed socially acceptable as relevant knowledge (the third face of power).

Taken together in the context of psychiatric medication management, 'power' as an obstacle to the defining aspects of SDM i.e: equality of knowledge; a full considered weighing up of options; and control by the service user, is an important theoretical construct in psychiatric medication management. However, the feedback arrows represent how both active resistance strategies and the interaction itself is important for also shaping the outer layers. The interaction and reflection at this level shapes the dominant discourse at the system level, both directly and indirectly via the relationship level. This is represented as being a continual process in flux, with movement and change occurring at each layer.

This Figure serves to structure thinking about how to explore the complex nature of SDM for psychiatric medication management, and acts as a framework for considering how power is enacted in this context. Ideas of experiential knowledge holding weight and a sharing of expertise, are fundamental to recovery focussed mental health service provision and for shared decision making, yet are often not explicit in models and policy. By exploring the construct of power in this context, it is hoped that increased insight into the

realities, and a grounded construction, of shared decision making for psychiatric medication management emerge.

The historical and policy context, literature review and conceptual framework for the thesis have been presented. The next chapter discusses the methodological choices for the research, attending to the underlying assumptions and research design of the study.

Chapter Four: Methodology

Chapter outline.

In this chapter the beliefs, values and philosophical assumptions for the research are explored. The design of the project is presented, identifying some tensions that arise as well as highlighting the potentially illuminating aspects of the chosen methodology. The first section describes the ontological and epistemological position of the research. This is followed by an examination of participatory ethos of the research, exploring how this enhances the knowledge produced. The third section focuses on an examination of the chosen data collection processes; semi structured interviews and recorded meetings. The fourth section discusses key decisions made in the approach to analysis. Ethical considerations and validation for the study are considered in the final section.

4.1 The Research Paradigm

4.1.1 Critical considerations

"Methodology is an area that connects issues at the abstract level of epistemology and the mechanical level of actual methods".

(Morgan, 2007, p. 123)

The chosen methodology has innovative qualities, seeking to apply established methods to new areas of investigation as well as offering an original approach to research methodology. Before the overarching paradigmatic approach is explored in more depth, key critical considerations of this research project which have strongly influenced the methodological choices, are considered.

Firstly, the research question and context have not been previously extensively examined. Therefore, this was predominantly an exploratory study, seeking to build understanding and knowledge, as opposed to confirming existing hypotheses. There was also a need to incorporate and embrace multiple perspectives from diverse participant groups. The following aspects were important considerations:

- A focus on both meaning and constructions, in addition to exploring overt behaviours.
- The acknowledgement of power inequalities between different groups in the study and the potential for this to hinder and limit exploration. For example the power imbalance between outsider researcher and participants, clinicians and mental health service users.

- The recognition that power and stigma may influence interpretation of findings is especially relevant to this research context. There was a need to increase the visibility and voice of member communities who have traditionally been marginalised in research, with appreciation of a wider value of enhancing social justice.

In addition, my background knowledge and beliefs are relevant to consider. I am an 'outsider' to the context being explored for this study and have very limited experiential understanding of mental ill health. I have come from a traditional academic background in the field of Psychology which influences my approach to understanding and choice of methodology. This contrasts with the background to this research. That is, the roots of this PhD lie in the wider local community which led to the formation of the research agenda, prior to my arrival to the PhD studentship. As such, there was a requirement for this research to acknowledge the need for change and make recommendations for practice.

4.1.2. Defining 'Research Paradigm'

Questions of methods are secondary to questions of paradigm, which we define as the basic belief system or world view that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways.

(Guba and Lincoln, 1998, p.195)

The term 'research paradigm' has a number of meanings (Morgan, 2007; Kuhn, 1970). The dominant view and expression of the research paradigm employed by social researchers over the last 30 years has been to focus on the version of a paradigm as an epistemological stance at the metaphysical level (Denscombe, 2008). The research paradigm in this sense refers to acknowledging the higher level belief systems underlying this study and exploring how this links with the research question.

Following this tradition, the paradigm includes the philosophical issues of ontology (or what is the nature of the social world we study), epistemology (or what counts as knowledge), methodology (or how to generate and justify such knowledge) and axiology (or what is the nature and role of values in social inquiry) (Greene and Hall, 2010). These levels of understanding will be explored in relation to social constructionism as the chosen paradigm for this thesis. First though, a brief overview of the broader historical context of key concepts within paradigm discussions is presented.

4.1.3. Historical context

During the 18th Century, Kant (1724 – 1804) influenced a new era for understandings of science and the creation of knowledge, through the appreciation of interpretation and understanding of beneath the surface or ‘inside the head’ processes. Kant’s criticisms of Cartesian objectivism, which relied heavily on science and reality only being that which is overtly observable and measurable, allowed researchers to also focus on the importance of interpretation, to knowledge production. As shown in the below quote, this era also resulted in a divergence away from traditional scientific reason and causal determinism, moving instead towards increased attention on complexity, in understanding of the applied social world.

The world of nature known by science is a world of strict causal determinism whereas the world of moral freedom (e.g. applied social research) is governed by autonomous principles which man prescribes to himself.

(Vidich and Lyman, 1998, p. 117)

Another important development in this time period was the development of the concept of lived experience and its role in understanding reality and knowledge (for example, see Dilthey, 1833 –1911). During the more recent history of the last 50 years, many critiques have emerged about both the Cartesian paradigm and neo Kantian research. Post positivism, along with other movements have in some senses resulted in a blurring of the historical and epistemological boundaries between qualitative and quantitative research. One outcome from these debates has been a re-emphasis of Kant’s interests with human freedom and social emancipation in research. Influential authors during this period (e.g., see Habermas, 1972) proposed social research to be understood in terms of an interaction rather than as a controlling process, with participants aiming for mutual understanding and for coordination of subsequent action.

4.1.4. Ontology and Epistemology

Drawing on the critical considerations proposed above in S. 4.1.1, it was essential to explore in depth multiple perspectives and identities, from diverse stakeholder groups, thereby increasing understanding of decision making practice in community based psychiatric medication management. This research acknowledges differing realities, explores the context and complexity surrounding these and consequently moves away from positivist notions of ‘one external observable truth’. I have therefore broadly adopted

a social constructionist¹⁸ research framework, with the aim of building an informed and sophisticated construction of medication management in mental health. In other words, this study has explored multiple intangible mental constructions, which are socially and experientially based and are dependent on the content of both the individual person and group to which they identify with (Guba and Lincoln, 1998; Burr, 2003). Knowledge in this sense is created as investigation proceeds, and is transactional in nature, with an emphasis on the *collective generation of meaning* (Guba and Lincoln, 1998, p. 240). The personal and variable nature of social constructions means that there is an emphasis on this knowledge being built through interaction and dialectical exchange between myself, co researchers and research participants. Thus, findings have been developed and explored throughout the entire research process, in an ongoing interaction.

However, while epistemological questions are paramount to the approach of this thesis, I do not argue that this automatically includes or excludes certain methods from being used. I rather adopt the view proposed by Guba and Lincoln (1998) that both qualitative and quantitative methods may be used appropriately with any research paradigm (p. 195). What is important is that the values and purpose of the research are made explicit through the justification of the methods employed. The aim of this thesis was therefore to explore multiple and diverse constructions of reality and compare and contrast these in an ongoing dialectical process with the end product being a more informed construction of psychiatric medication management (than those of previous constructions). However, this includes as a priority, the *emic* (or meaningful to the actor) perspective of the participants and researchers through the process.

4.1.5. The role of theory

This is an exploratory study with emphasis on building theory from the socially constructed realities, in this context. However, as part of the theory building component of this research, there is also part of this study which explores *etic* (*observed or culturally neutral*) concepts of understanding (for example, shared decision making). However this sits within a social constructionist framework which aims to use this aspect of the process to broaden and inform a more sophisticated construction.

¹⁸ The term Social constructionism/ist (as oppose to constructivism/ist) was seen to represent the research framework most appropriately. For further discussion see Burr, 2003; Lock and Strong, 2010; Crotty, 1998

To clarify then, I reject the positivist notion that it is possible to obtain one real truth and as illustrated in the below quote, I do not aim to reach one single overarching theory.

...it might be possible given a coherent theory to derive by deduction what facts ought to exist, it is never possible, given a coherent set of information, to arrive at a single ineluctable theory.

(Guba and Lincoln, 1998, p.199).

Therefore, the concepts or models explored in this thesis are not being used with the aim of establishing real truth, but rather to assist with the process of broadening how shared decision making for psychiatric medication management is framed within the social, political and cultural context. Within this framework there is a focus on a call to action and social change as one of the goals. I adopt Habermas' perspective that social research is an interactive rather than controlling process.

Participants aim for mutual understanding over the coordination of their subsequent actions. Applied research, therefore is not about social conformity but about social justice.

(Habermas, 1972, p. 117)

Within social constructionism there are a number of different versions and strands which have emerged. I believe this thesis sits within Guba and Lincoln's (1989) constructionist paradigm which values a pluralist and relativist approach. That is, recognising that multiple and conflicting constructions are potentially meaningful.

The role of language needs to also be accounted for in this study. Although I acknowledge that experience is a socially constructed process and language is at the heart of this construction process, I am less interested in how language structures thinking. Instead this study focuses more on how language is used by people to actively construct accounts, and build defensible identities and versions of events in the interaction (Burr, 2003). Additionally the study acknowledges that conversation has locally determined meanings (Lock and Strong, 2010).

4.2 Methodology

It is not easy to say something new; it is not enough for us to open our eyes, to pay attention, to be aware, for new objects to suddenly to light up and emerge out of the ground.

(Foucault, 1969/1972: pp.44-45)

A participatory methodology has been adopted for this study. A participatory methodology is compatible with and sits within the social constructionist framework. The study emphasises multiple identities and favours an approach which emphasises interaction and reflection throughout the research process.

4.2.1. A definition of Participatory Research

Participatory research (PR) rests on the recognition of power differences and the implications of these differences for problems of discrimination, oppression, misrepresentation and marginalisation (Mertens, 2009). It acknowledges that versions of reality are socially constructed and emphasises that the relationship between the researcher and participants is a critical determinant in achieving a sophisticated construction or understanding. The nature of the relationship is characterised by close collaboration between researchers and participants attempting to reduce the power differential, with specific attention given to issues of communication and power.

The importance of examining power inequalities is especially relevant in mental health research. The conceptualisation of mental illness has a long and infamous past and stigma remains a key challenge. In addition, historically, mental health services have been associated with paternalistic and coercive practice. See chapter one for further discussion. For the purposes of understanding for this chapter, it is sufficient to state that a specific power dynamic is applicable to the context of the study. The methodological choice of adopting a participatory methodology encourages these power dynamics to be challenged and made more explicit, through reflection and involvement, with the aim of bringing new insight to the research questions.

4.2.2. Historical context of Participatory Research.

The origins and development of PR are broad and complex. This is not only because the term is used loosely, and interchangeably with concepts such as action research, but it is also because participatory research is a blend of a broad range of research approaches and epistemologies that include: participatory action research, emancipatory research, action research, feminist critical approaches, transformative education and critical ethnography (Sarch, 1996).

It is nevertheless possible to outline some roots over the previous few decades. For example, Friere (1970) focused attention on how social science research could be used as a tool to relocate the everyday experiences and struggles of the marginalised in society, from the periphery towards the centre of inquiry. Embracing emancipatory principles, the aim of this research was a process centred on what Friere called *conscientisation* where the marginalised were to become agents of social transformation aimed at creating more democratic societies (See Sarch, 1996 for an overview). Another strand in the development of PR is related to its action component and a branch of PR known as PAR (participatory action research). What is distinctive about action research is that rather than the focus being on a process of description, the research is focussed on the process of action, via action cycles. The main aim of participatory action research is not only to improve the understanding of a situation, but to attempt change, learning and building knowledge during the change process (Munn Giddings and Winter, 2013).

Although the history of action research is connected with the development of PAR, it nevertheless can be distinguished from it as: having European/American origins; having academic origins; and focusing on the improvement of professional practices. Action research has been adopted in some areas of the social sciences (for example, organisational psychology and sociology) and has been criticised in this context as excluding some of the emancipatory principles paramount to the participatory research ethos. For example, research adopting PAR methodologies in the area of management practice or organisational change programs with aims to further strengthen existing power and dominant conceptual practices.

As such, the role of language and mainstream concepts and frameworks need to be mindfully employed by practitioners of PAR and other forms of PR. According to Sarch (1996) these have to be carefully considered when looking at the construction of the research questions, the methods employed and the analysis of contexts explored. It is also acknowledged that the power differential between the professional researchers and participants will not necessarily be overcome through increased participation alone. Thus researchers need to approach studies that claim a participatory methodology cautiously and not assume that just because participatory methods have been used, that this necessarily bestows the research with emancipatory features.

4.2.3. Participatory methodology and knowledge development in mental health

One of the most important aspects of conducting a participatory study then is to set up the research process in such a way that it enables the research to challenge conventional hierarchies of knowledge, instead embracing perspectives which may have previously been ignored using other methodological approaches (Munn Giddings and Winter, 2013). The involvement of service users in the research process is therefore fundamental to this study. The concepts of involvement of service users in health and social care research has been on the increase since the 1980s, with a number of movements by mental health service user, carer and other advocacy groups campaigning for their perspectives be incorporated into mainstream policy and research.

Since the early 1990s, Health and Social Care legislation and research governance in the UK has put in place measures to encourage involvement of service users and carers in research, with, for example, the RandD body 'Involve' leading initiatives in the NHS. In addition, statutory research networks, such as the mental health research network (MHRN) now have a requirement for user involvement in research, and findings have started to find their way into international peer reviewed journals. However there has been scepticism in some areas of academia and resistance to claims that such inclusion adds any value. It has been suggested that a tokenistic, 'tick the box' consultation approach is often pursued (Beresford, 2002; Turner and Beresford, 2005; Cotterell et al, 2008). Nevertheless, there appears an ongoing positive shift. For example, recent NIHR¹⁹ funded mental health research projects have received prestigious accolades for their emancipatory focus (e.g. Brandon et al, 2013).

¹⁹ National Institute for Health Research

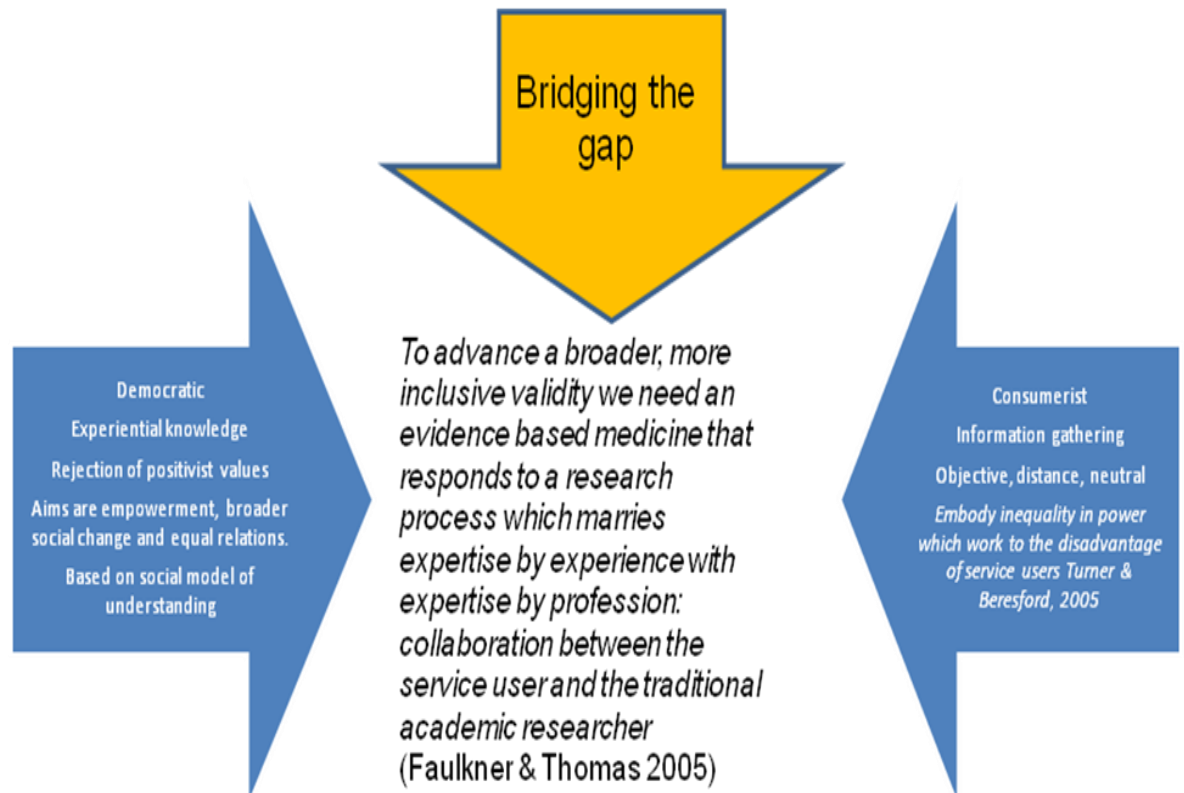


Figure 7. Faulkner and Thomas (2005) - The competing values and traditions of participation in research

In summary and as represented by Figure 7 above, participation in itself does not necessarily result in a sharing of power. Consumerist approaches may be employed where information gathering approaches to participation lead to 'objective' distant and neutral approach to knowledge and understanding. It has been criticised that participation in this context may actually, '*embody inequality in power which result to the disadvantage of service users*' (Turner and Beresford, 2005; p.vi).

Reflecting on the participatory elements of this research then, I am conscious about the limitations imposed by the context of this research (theory building for the purposes of a PhD) and my knowledge and skills (I come from a traditional academic background with limited experiential understanding of mental illness). I therefore cannot claim a fully emancipatory purpose or value to this project. However I feel it important to focus on how increased participatory methodologies may add original insight to the research question, may assist the research process, and may encourage reflection on practice and promote subsequent change. Acknowledgement of existing power imbalances is important for this research, with the aim of maintaining, where possible, a more democratic theoretical lens to knowledge and theory development. As such, there is a need for me to bridge the gap between what may be considered a traditional PR study embracing democratic values on

the one hand, and a consumerist approach to participation in research on the other (Beresford, 2002). The quote from Faulkner and Thomas (2005) in Figure 7 is useful in this respect, acknowledging the importance for the research to respect an equality of knowledge and view the co-production as a joining of 'expertise by experience with expertise by profession'. It is by adopting these values that I hope to be able to embrace participatory methodologies.

In summary there is a variety of participatory approaches. The participatory approach utilised in this study aims to generate knowledge and to analyse accounts in a collaborative way.

Within mental health the benefits of participation to patients and providers in service development and evaluation is well documented, including, amongst others, empowerment of individual researchers and improved communication between service users and providers (Simpson, 2008). Research is also emerging which emphasises the benefits of participatory approaches on knowledge production, which as discussed above, is an important consideration for this research. Studies have shown that service user researchers enhance rapport and reduce participants inhibitions and may overall boost recruitment and quality of data (Faulkner et al, 2008). Rose (2003) suggests that service user researchers offer new types of evidence and offer fresh insights through a reduced distance between direct experience and its interpretation. Other research in this area also shows that peer researchers may produce qualitatively different findings than traditional academic researchers, with co interviewers focusing more on experiential understanding and traditional academic researchers focusing more on process and policy implications (Gillard et al, 2010; Neil et al, 2013).

Following on from this, it is important to consider how to pair these potential differences in the analysis and move towards a new and shared understanding? Figure 8, adapted from Gillard (2011), shows the proposed approach to knowledge production, sought for in the participatory elements of the PhD.

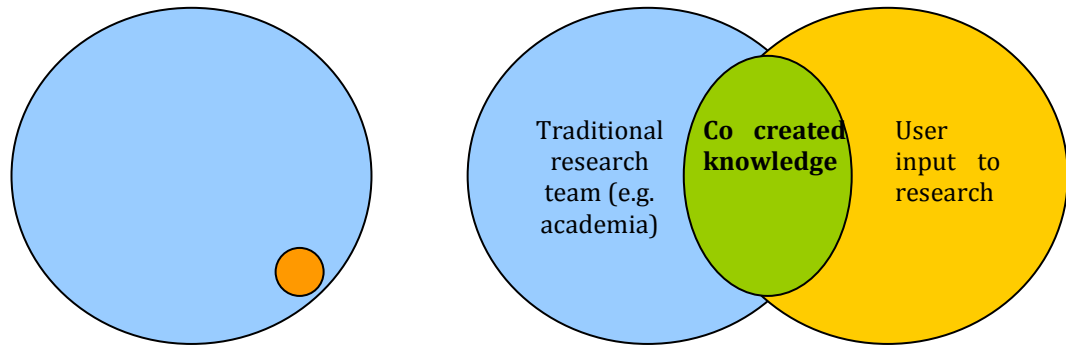


Figure 8. Participatory input to knowledge creation (adapted from Gillard et al, 2011)

On the left diagram a more traditional consumerist approach is illustrated, with the service user contributions being very much on the periphery of knowledge produced, having little control over this aspect of the research. The model on the right reflects more the situation I have aimed for in this research. Here my expertise as the traditional researcher overlaps with co researchers' contributions, combining to produce co created knowledge. It is in this aspect that new and fresh insight to the research questions may be gained.

As such there are two aspects to consider in relation to the participatory ethos of the study; the type of activities that mark a participatory research project and the values implicit to the project.

4.2.4. Key decisions relating to participatory methodologies in the study

Key elements which seek to embrace the values and methodologies of participation in this study include:

- The formation of the research advisory steering group
- Use of co researchers
- Training provision from South Essex Service User Research Group
- Collaborative data analysis
- Collaborative dissemination and reflection phases

Further details of the first component: 'formation of the advisory group', is presented below. Other aspects are explored in some more depth, in section.4.3.4 and 4.4.1.

Formation of the research advisory group

The research advisory group was formed early in the research programme, in June 2010. This group consisted of one community psychiatric nurse, one psychiatrist, three service users and one carer. This mix was chosen to reflect the participant groups which form part of the study, with a weighting given to contributions from service users in the group, providing key experiential understanding of the topic. All members, except one, remained part of the group for the full lifecycle of the project.²⁰ Attendance was good, with most members attending each meeting.²¹

Recruitment for service user members of the group took place via an advertisement sent through the RandD team within the local NHS foundation trust. Initial response to the advert was good and therefore a selection process was necessary. Informal interviews were conducted by the RandD manager and myself, focussing on the persons' interest and relevant personal experience to the topic. Less importance was placed on other skills for the role (e.g. research experience and skills). All recruited service user members had personal experience of being prescribed psychiatric medication, falling into the categories of anti psychotics and mood stabilising medication. All members have had varied and numerous experiences of decision making about psychiatric medication.

Since its formation the group met approximately once every two months²². In these meetings I provided relevant updates and facilitated discussions on current research processes. Although some initial planning had been put into place prior to the formation of this group, the group also had some input into the preliminary planning phases. On reflection, however, and given the context of this research process sitting within my PhD, it would be true to say that initial key decisions surrounding the research questions and data collection remained in my control during these early phases with more of a consultative ethos being present. More collaboration was achieved in the later stages of planning, for example while planning the recruitment strategy and designing topic guides for research interviews. See appendix I for minutes taken from an advisory group meeting in this phase of the research process.

²⁰ The psychiatrist member left the group six months after its formation due to a change in personal circumstances.

²¹ One service user member was unable to participate as a co researcher due to a period of illness, but returned to the group during the later phases of the research.

²² In the planning phases meetings were held more frequently. In the latter phases, post analysis, meetings occurred less frequently.

During the research process I strived for an approximate democratic approach, maximising choices and decision making where possible. Throughout the research life cycle, the group maintained its focus on sharing knowledge based on experience as people who have been prescribed psychiatric medication, as a carer to someone being prescribed psychiatric medication or as a medic involved in the decision making about psychiatric medication. The research remained relevant and in tune with the experiences of members. However, over time the group developed, and identities of individual members and the group as a whole, changed. Familiarity and confidence grew and friendships were formed, and by the end of the research cycle the group existed as a collective identity for the project, as opposed to a group of individuals with particular roles. See appendix II – the research diary²³.

4.3 Research Design

4.3.1. The research context.

The study has been conducted in Cambridgeshire, in the East Anglia region of England. Cambridgeshire as a growing population recorded at approximately 600,000 in 2010 (Cambridgeshire County Council Research Group (CCCRG), 2010). The vast majority of the sample (minus 3 service users and 1 psychiatrist) were recruited within Cambridge itself. Cambridge is a highly affluent city, hosting two universities and resultantly has the highest proportion of its population aged between 16-39. It is a growing city with a reputation for small start up and high tech industry, with the wider area of Cambridge known as 'the silicon fen' in the business community. Medicine is one of the growth areas of the IT development and of pharmaceutical initiative in Cambridge. It is estimated that the City will grow by 28% by 2031 (CCCRG, 2010). Education levels are far higher in the local population than other parts of the UK. Almost double the national average of residents are educated to degree level, or above (CCC, 2012). Other parts of Cambridgeshire are rural, and suffer from poor transport networks.

The remainder of the participants from this study were from Huntingdon (n=3) and Peterborough (n=1). These dwellings both have different socio-demographic contexts. Huntingdon is a smaller market town, with a good rail and road network and a high proportion of its people are economically active (CCC, 2012). Peterborough is a larger city, and has a population of 189,000. (Peterborough County Council, (PCC, 2011). It is also

²³ Also in appendix VII a transcribed group meeting during the collaborative analysis phase is presented

economically active, but with higher than average numbers of people with no formal qualifications and other unrecognised forms of qualifications (PCC, 2011).

The wider Eastern Region of England has the fifth largest population of non White-British residents in the UK, with 7% of the non White-British population. However it has slightly smaller proportions of all Black and Minority Ethnic (BME) groups than are present in the overall population (Dunn, 2005). Cambridge hosts the largest number of people from the Chinese community and one in five of the city's residents are foreign nationals (Oxford Migration Observatory, 2013). Peterborough has a higher than average proportion of white: EU (non British) residents (PCC, 2011).

4.3.2. The treatment setting

The study took place within a NHS foundation trust that provides secondary care mental health services. Participants were recruited from within a community mental health team / pathway (CMHT). The pathway served approximately 260 people with diverse needs, who were broadly considered to have severe and potentially enduring mental illness. This diversity was an important consideration for choosing which pathway to focus the study within. Multidisciplinary working was employed, and each person was assigned a care coordinator. The pathway operated in the context that a standard maximum time for treatment was in the region of eighteen months for any one point of contact. This is not to say that some people wouldn't have had extended contact beyond the eighteen months period, but if this was the case it was likely to be through repeated separate contacts with the service over a number of years. As such there were close links with other parts of the mental health service provision and primary care provision (e.g. GPs). The service provision was diverse although its broad aim was to act as a first point of contact for people with secondary care services. It is important to note that there were on going re-organisational changes in the provision of care pathways during the time of the study. Changing accountability and relationships between primary and secondary care, alongside many cost cutting pressures, resulted in a highly unstable period during which the study took place.

4.3.3. Data collection process

To recap, there were two overarching research questions for this thesis:

What are stakeholder views about SDM for psychiatric medication management?

How are decisions about psychiatric medication made in practice?

As shown in Figure 9, there were two phases to the data collection process. Throughout, data collection procedures were qualitative in nature (semi structured interviews and digitally recorded meetings). Data analyses techniques were also informed by a qualitative approach (namely thematic analysis and an applied conversation analysis). Phase two (recorded meetings), represented using a smaller box in Figure 9, supplemented findings from the thematic analysis in phase one (research interviews). Initially, a supporting role (indicated by the internal box shown in the diagram) was planned for a quasi quantitative analysis method, namely the OPTION scale, in the analysis of phase two recorded meetings. The OPTION (acronym for “observing patient involvement”) scale is aimed at measuring the level of Shared Decision Making behaviours of psychiatrists. The scale was chosen for inclusion in the analysis to supplement the theory building elements of the analysis process. However following initial analyses using this scale, I decided that it added little value to the overall data and subsequently removed it from the overall findings. Please see appendix IV for further details. Throughout the research, a participatory theoretical lens was present, guiding the research process and methods employed.

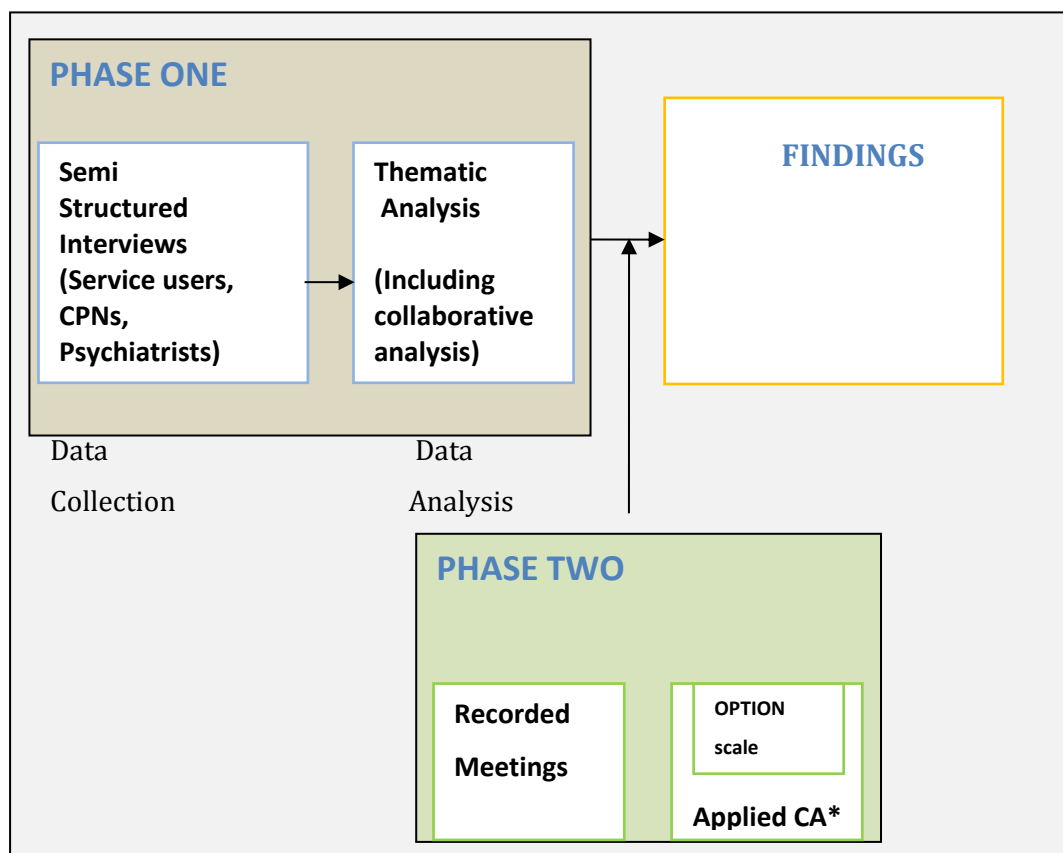


Figure 9. Data Collection Process

4.3.4. Sampling and recruitment.

Phase one

Thirty interviews were undertaken. Interviews were conducted with mental health service users (n=15), psychiatrists (n=7), and CPNs (n=8). These three participant groups were chosen for inclusion following a scoping review with key stakeholders within the NHS foundation trust²⁴ in addition to discussion with the research advisory group (see above). Although the role of other key stakeholders (for example GPs, carers, other mental health practitioners and pharmacy services) is acknowledged, these groups were not included for feasibility reasons. Equal weighting was given in data collection for service users and practitioners.

Practitioners

All psychiatrists (n=8) and CPNs (n=9) from the CMHT pathway in the local city where the study took place, were approached for participation²⁵. Informal networks and communication between myself and staff within the pathway, assisted the initial communication and invitation process. I attended a team meeting to provide some initial information to the wider group of practitioners. To promote recruitment I also met individually with senior members of the team (consultant psychiatrists and CPN team leaders).

Service users

Psychiatrists and CPN care coordinators within the team were asked to identify suitable potential service user participants for inclusion in the study. The inclusion and exclusion criteria is shown in Figure 10.

Identification of Service User participants

Key inclusion criteria.

The practising psychiatrist and/or CPN care coordinator will be asked to recommend people for inclusion who, in their professional opinion:

- (1) have adequate mental capacity for informed consent.
- (3) receive services from within the specified care pathway.
- (4) have had contact with secondary mental health services for a minimum of 6 months
- (5) are an adult

Figure 10. Inclusion criteria in the identification of service user participants

²⁴ Meetings were undertaken with the chief pharmacist, chief psychologist, two consultant psychiatrists and the director of psychiatric nursing, in addition to observing a ward round in an inpatient setting.

²⁵ One psychiatrist from another nearby town (from the same pathway) also formed part of the sample.

First contact about participation was made by the practitioner or psychiatrists' secretary, where a full participant information pack, invitation letter, reply slip and self addressed envelope was provided. This process did incorporate a level of bias into the identification and recruitment process in that practitioners may have identified potential participants based on other factors (e.g. existing good relationship established etc). However, the chosen identification process conformed to relevant data protection legislation and best practice guidelines. Throughout the process, clinicians were encouraged to adopt an inclusive process of invitation for their client base (within the criteria set), and I emphasised the importance for this study to explore the views and experiences of service users.

Nevertheless there were challenges in the strategy to recruit service users, via gatekeepers. Originally I had planned for 30 interviews to be conducted with service users, but 15 interviews were actually undertaken. Although various strategies were incorporated to promote relationships with clinicians in the team, including; regular contact via email and phone calls; escalation meetings with senior clinicians and management; dropping in and standing in the team office; nevertheless a research fatigue appeared to hinder the recruitment of service user participants to phase one. This subsequently impacted phase two recruitment possibilities.

Even when support for recruitment was directly offered by gatekeepers, this often did not result in the actual invitation packs being sent out to service users. Practitioners mentioned being involved in multiple research projects during this time period, and a general time pressure appeared to hinder the ability and willingness to ensure information packs were being sent out to potential participants. This is discussed further in the Limitations section of the Conclusion chapter (10.4) and relevant research diary entries in appendix II.

Consequently a second phase to the recruitment of service users to phase one was also undertaken, following these initial recruitment challenges. Leaflets were created and left in the reception area of the CMHT outpatient clinic, as well as the locally based mental health organisations. Interested potential participants subsequently contacted me directly, before the specific inclusion criteria was considered. This therefore conformed to the data protection requirements of the process, while avoiding some of the bias and challenges associated with use of gatekeepers in the original recruitment process.

Phase two

A convenience sample was adopted for phase two of the study (recorded meetings). People who participated in phase one (and who gave consent) were approached at a later date inviting them to participate in phase two. Service user participants then provided details of a forthcoming meeting where medication was to be discussed. I contacted the relevant practitioner to seek consent for the proposed meeting to be recorded. Written consent was obtained directly prior to the meeting. All participants in this phase had also participated in the interview (phase one).

A diverse range of meetings (n=10) was sought for in this phase, incorporating meetings between the psychiatrist and service users (for example, as part of a routine outpatient clinic) as well as more informal meetings between service users and CPNs (as part of home visits, for example). However there were 'knock on' recruitment challenges for this phase also. In particular, a far smaller pool of potential participants were available, given the recruitment difficulties in phase one. In addition, phase one recruitment was a protracted process over a number of months, and as such often significant time had passed and consequently people were no longer receiving services²⁶, at the time I contacted them about participation for phase two. As a consequence of these difficulties, only four meetings were recorded between one psychiatrist and four service users²⁷.

4.3.5. Data collection methods

The chosen methods are suited to the research questions. Qualitative data collection methods were chosen for both phases of the research, with the aim of bringing to the surface hidden meanings and social constructions of psychiatric medication practice. These methods are suited to investigations, such as these, which are currently under researched, having a strong theory building emphasis.

The combination of interviews and recorded meetings allowed for both views and socially constructed attitudes to be explored, in addition to examining overt discourse in psychiatric medication management practice. Overall the combination of these methods allowed for a rich and insightful picture to be drawn about medication management practice in a community based psychiatric service.

²⁶ From the team within which the study took place.

²⁷ Further discussion on the sample for phase two is presented in the Conclusion chapter

Phase one: Qualitative interviews

The first phase of the research explored the socially constructed views of key stakeholders about the involvement of service users in psychiatric medication management. The interviews were semi structured using open ended questions. The overall focus of the interview was to explore the participants' views and (recent) experiences of psychiatric medication management. Interview schedules were developed in conjunction with the advisory group and consisted of a separate version for practitioners²⁸ and service users. A copy of the interview schedules can be found in appendix III. Both interview schedules comprised of three main sections: Section one explored general background questions relevant to the topic. Section two explored the participants' general views and experiences of medication management, perceived enablers of and barriers to SDM, and opinions around involvement of service users in decision making about psychiatric medication. Section three explored some recent examples of meetings where medication was discussed. These critical incidents or concrete events were specific meetings that had occurred recently (within 6 months) and were poignant to the participant. The use of this style of questioning is known to be effective at bringing to the surface more subtle and hidden views, less likely to be retrieved along a more general line of questioning (Flanagan, 1954). Participants were asked to focus on one positive and one negative meeting where psychiatric medication was discussed, that had an impact or stood out for the participant. After establishing the details of the event, participants were asked if, *in hindsight they would have done anything differently?* This allowed for values and views of collaborative decision making to be explored and for current practice to be better understood.

Interviews with service users lasted for approximately 30 minutes - 1 hour²⁹. Interviews with practitioners lasted approximately 45 mins – 1 hour 15 minutes. The decision for a shorter interview with service users was jointly made as part of the research advisory group where tiredness was considered a potential issue for wellbeing of participants. All interviews were recorded using a digital audio recorder and transcribed using standard conventions. For interviews with service users, there was a small token of thanks (£10 cash). Interviews in phase one took place in a neutral location, on university premises or in NHS sites³⁰.

²⁸ The same interview schedule was used for CPNs and psychiatrists

²⁹ Initially 45 minutes maximum time limit was proposed by the advisory group, but this was exceeded for some of the service user interviews

³⁰ All practitioner interviews took place within NHS sites

Co researcher team

The decision to use co researchers in the data collection phases of the research was made towards the end of 2010 in collaboration with the research advisory group. Initial interest in these roles was expressed by the three service user members of the advisory group and the carer member of this group³¹. The role of co researchers was to conduct interviews with other service users in phase one of the data collection. Co researchers acted as the lead interviewer and I was present as a second interviewer. In the majority of these interviews, my active role was very minor, usually only asking a maximum of one or two questions, at the end of the interview.

It was initially envisaged that co researchers would act as sole interviewers. However, following challenges in the recruitment of participants, this strategy was changed. The reasons for this were that there were less interviews than planned, taking place over a longer time period. Co researchers expressed that given the longer time periods between interviews they would prefer myself as CI to also be present. Given the reduced number of interviews, I also was keen to attend as many interviews as possible.

A debriefing and reflection session took place following each interview. The debriefing session comprised of a discussion of key themes emergent from the interview and reflection and feedback on the interviewers' questioning and style. Reflection about wellbeing and or distress caused by the interview also formed part of this session.

Training provision

Interview skills training was provided to co researchers. I decided to employ the South Essex Service User Research Group (SE SURG)³² to assist with the initial training. SE SURG have been involved with many service user led research projects nationally and provided invaluable insight and specialist training, bespoke to this project. The use of SE SURG also benefitted the project in that I was able to participate equally as one of the group in the training session, thereby reducing initial power imbalances between myself as both chief investigator and trainer, and co researchers. This was an interactive one day session which drew on existing experiences of the co researchers and reflected on some common pitfalls in co researcher led interviews. The use of role play, discussion, feedback and reflection was incorporated into this initial session. The session received positive feedback from all members of the team.

³¹ One service user member was later unable to undertake research interviews due to a period of illness.

³² An expert service user research and consultancy group, affiliated with Anglia Ruskin University

This training day was followed by three further sessions, facilitated by myself, applying the learning and skills from the first training session to the interview schedule. Role plays and practice of interview scripts were especially useful in this aspect of the training.

Further one to one training was conducted with co researchers, depending on levels of confidence and ability prior to undertaking the first interviews. All co researchers opted to act as the second interviewer for the first interview undertaken. For these first research interviews I acted as the lead interviewer, with the co researcher asking additional questions when desired. All subsequent interviews were led by co researchers (see above).

Phase two: A study of current practice

This phase examined current practice in psychiatric medication management, focussing on the dynamics of the conversation. As mentioned above (S. 4.3) four practitioner – patient meetings were audio recorded and transcribed. These meetings were review meetings, taking place during outpatient clinics, on NHS sites. The four meetings involved the same clinician, a consultant psychiatrist operating with the community care pathway. Each meeting involved a different service user. Both the practitioner and service users had participated in the research interview (phase one). A researcher was not present in this phase, allowing for less intrusion and contamination of the data. The digital recorder was operated by the clinician in the meeting.

This part of the research supplemented the findings from phase one, by comparing discourse in action (in this phase), with the views and experiences explored in phase one. A case study approach to the analysis was adopted (see below). A particular focus of this phase was to explore the power claiming and power giving strategies employed by participants, thereby examining the extent of involvement and shared dialogue between the psychiatrist and service user, when medication options were discussed.

4.4 Data Analysis and Validation

4.4.1 Analytical techniques employed.

4.4.1.1. Thematic analysis

Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun and Clarke, 2006, p.82).

Thematic analysis was employed for phase one (the research interview). According to Braun and Clarke (2006) a *'theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set'* (ibid: p. 82). Thematic analysis is, however, a broad term and may result in many interpretations and approaches to the analysis process.

A key decision in the chosen approach to thematic analysis for this thesis was the focus on providing a rich description of the entire data set as oppose to a detailed account of one particular aspect. An inductive approach (Patton, 1990) was employed. Therefore themes are strongly related to the data, with less importance placed on the relationship to specific questions that were asked in the interview³³. The themes were continually reviewed in relation to the research questions and a collaborative approach to theme building was chosen (see S. 4.4.1 below).

Although the process of analysis was recursive (as oppose to linear) it is useful to map out key phases to the analysis process. I followed the Braun and Clarke's (2006) phases of thematic analysis:

- *Familiarising with the data*
- *Transcription of verbal data in verbatim and checking against audio recordings*
- *Generating initial codes. Here codes refer to the most basic segment or element of the raw data that can be assessed in a meaningful way regarding the phenomena*
- *Searching for themes. Here a collection of candidate themes and subthemes are identified and all extracts of data are coded in relation to them*
- *Reviewing themes*
- *Defining and naming themes, providing a description of the essence of what each theme is about*
- *Producing the report.*

(ibid, p. 88)

The software package 'N Vivo' (version 10) was used as a tool to assist the coding process. In the region of 450 pages of writing were transcribed from the 30 research interviews that took place between June 2011 and July 2012. Themes were explored for each stakeholder group (Service user, CPN, Psychiatrist). See appendix V for N Vivo coding frames and themes, for each stakeholder group. Relevant entries from the reflective diary (appendix II) also details how themes were developed over time.

³³ Although note below, regarding incorporation of dual coding process.

Whilst an inductive analytical approach was pursued, during the coding process I decided that, for increased organisation and exploration of particular aspects of the interview, coding by interview structure would also be helpful³⁴. As such, a dual coding process took place, where text was coded according to data driven themes and also by what part of the interview it took place (so termed structural coding). I didn't see the need to adopt a question by question coding strategy. Instead the structural coding was comprised of five sections with sub sections, incorporating specific questions, where appropriate. This is illustrated in the N Vivo screenshot taken from the psychiatrist structural coding, shown below:






	Section 1 - Intro - roles in med management
	Other practitioners
	role of carer
	role of cpn
	role of psychiatrist
	Section 1 - Intro and background
	Intro - changes over time
	Intro - how important is psychiatric medication in mental health treatment programs in ITT
	Intro - Q How would you describe your approach or style in consultation meetings
	Section 2 - conceptualising SU involvement
	Ideal world, how involved should SUs be
	Problems with involving people in decisions
	Section 3 - Examples of success
	Section 4 - Examples of failure

Table 3. N Vivo screen shot of psychiatrist structure based coding

Themes emergent from critical incident questions (positive and negative meeting examples) were embedded within the data driven themes. However, where differences

³⁴ Also see relevant entries from the research diary, appendix II for further details

emerged between the critical incident and general questions component of the interviews, these were highlighted in the presented findings.

4.4.1.2 Collaborative data analysis

In keeping with the participatory methodology for this study, I decided upon a collaborative analytical approach. I have followed the suggestions of Cotterell (2007) and his seminal participatory work on the needs and experiences of service users with life limiting needs, and adopted a two stage collaborative analysis process.

Training in the analytical process was provided for the advisory group in a one off workshop, facilitated by myself. The focus of the work shop was to encourage discussion and reflection as a group, focussing on practical discussions about good practice in analysis and the role of the researcher. The process of thematic analysis also formed part of this training session. Additional guidance notes were provided to members of the group, following the session.

For stage one, I conducted initial thematic coding of interview transcripts, occurring during the data collection phase, in phase one. Stage two occurred after data collection and was a collaborative analysis. The emphasis in this phase adopted some of the perspectives favoured by Munn Giddings and Winter (2013), focused on learning and new ideas, rather than on description and pure interpretation. As such this phase to the research was especially relevant to encouraging fresh insights into the phenomenon as opposed to confirming existing thoughts around the topic. The collaborative analysis process was only adopted for the analysis of service user interview data, in phase one³⁵.

In total, eight collaborative analysis meetings took place with members of the research advisory team. Good attendance was observed throughout this phase, with the CPN, service user and carer members attending the majority of meetings. The collaborative phase consisted of coding and interpretation of transcripts and theme building sessions. Differences as well as overlaps between my initial coding and the groups' interpretations were explored, building consensus through discussion.

³⁵ A collaborative approach was not adopted for practitioner interviews (where co researchers were not directly involved in the interview process), or phase two (as a result of the lengthy additional training requirements needed).

The first six of these sessions involved the reading of an interview transcript³⁶ and exploration of emergent themes. Members were sent a transcript in advance of the meeting, for reading and preparation, along with preparatory guidance notes. I facilitated the meetings in a structured way, assigning turns to speak and ensuring each member of the group presented their individual interpretation of the transcript, before a more open discussion ensued. I was careful not to guide the discussion and did not present my initial coding for the transcript until the end of the meeting, at which point any differences between my individual coding and the group were explored.

The style and content of these meetings, however, developed over time. The first meeting was lengthy (over two and a half hours) and involved a detailed coding of the transcript. At times, in these early sessions, I spent time ensuring that the themes and interpretations discussed were grounded in the transcripts being explored. Often discussions of emergent themes were highly poignant to advisory group members' own personal experiences, and this added to the interpretation and discussion of themes. Conflicts and differing interpretations from the transcript were also explored as a group, requiring, at times, more structured facilitation³⁷. However, towards the end of the six sessions, less structured discussion was needed. Instead these latter meetings focussed on comparisons of the transcript to previous transcripts analysed, and emergent themes were explored as a group.

These collaborative analysis meetings were recorded using a digital recorder and later transcribed. By adopting this approach I was able to return to the content of these meetings and compare themes emergent from the group meetings to the initial thematic analysis I had already undertaken on the transcripts. Please see appendix VII for an example transcript from one of the collaborative analysis meetings, and the associated coding framework which was later incorporated into the findings.

For the final two collaborative analysis sessions, reflection of broad themes and content was discussed. I was again conscious not to overly dominate these sessions by presenting my existing analytical work. However I was also concerned that by not offering any structure, these sessions would become confused. As such I decided to ask the group at the start of the session of their preference for the structure of the meeting. All members opted for me to present some initial theme and sub theme headings, before subsequent

³⁶ Six service user interview transcripts, out of 15 in total were subject to this process.

³⁷ For further reflection on the collaborative analysis process, please see the appendix.

discussion. This worked well, probing exploration of the themes in relation to previous transcripts. As a consequence of these sessions, the thematic analysis developed and themes were adapted, added or changed in response to the group discussion.

4.4.1.3 *Applied Conversation Analysis*

An applied conversation analysis (CA) was adopted for phase two of the data collection process. Applied conversation analysis, and more generally, discursive analysis is concerned with how particular versions of reality are manufactured, negotiated and deployed in conversation. The social constructionist paradigm for this thesis resulted in applied CA being a compatible and informative approach to adopt (Willig, 2008). A key feature of social constructionism is the recognition of the fact that different constructions of the world sustain different kinds of social action. It is widely thought that within this, our constructions of the world are founded upon language, and as such language underpins the form of action that it is possible.

The focus of using applied CA within this thesis was to explore the situated use of language in social interactions. (as oppose to adopting a more deconstructionist position on language) (See Burr, 2003 for further discussion). As such, an emphasis was placed the importance of accountability and stake in conversation (Edwards and Potter, 1992). Here, discursive devices and constructions are seen to be used in conversation in order to further the participants' interpersonal and social objectives. Consequently, the recorded conversations were analysed to understand how conversation and discursive repertoires were being used strategically to pursue the participants' objectives, acknowledging that conversation has *locally determined meanings* (Willig, 2008; Labov and Fanshel, p.273, cited in Lock and Strong, 2010).

In recent decades there has been a blurring of distinctions between different forms of Discourse Analysis (DA) and Conversational Analysis (CA). According to ten Have (2007) applied CA is *asking why it makes sense, for participants, locally, in their practical context, to do things as they are done, even if this is at odds with how these practices are planned, evaluated or accounted for 'elsewhere' 'in theory' or at higher hierarchical levels in an organisation* (ibid, p. 196). The key distinction between this form of CA and more 'purest' forms of CA is the emphasis placed on the broader consideration of the participants' context, goals and perspectives, as opposed to a traditional CA study which would be interested in the micro speech activities in their own right. The chosen analytical approach

makes use of the knowledge of speech activities, turn taking and linguistic patterns in the analysis of four recorded meetings, whilst keeping focus on the important contextual information further informing the understanding of how the pattern of discourse may be relevant for the participants in this context. Interview data was incorporated into the analysis, to provide additional depth and discussion of the data in this phase. A case study style for presentation of findings was also adopted, allowing for a rich and contextualised analytical approach (see Chapter Eight, for further discussion).

In summary, CA (and DA) has been criticised because it does not explore 'why' particular participants pursue certain objectives. This thesis uses applied conversation analysis to explore the 'what', in conjunction with 'why' through use of both a case study based presentation of findings in phase two and the thematic analytical approach for phase one. This enables a comprehensive and rich construction of psychiatric medication management to emerge.

An important consideration for this thesis was the amount of time required to transcribe the original data into a written format suitable for the analysis. A relatively small sample of four recorded meetings was beneficial in this regard. Also a reduced adaptation of the traditional CA transcription (Atkinson and Heritage, 1984) was used, which, whilst retaining the key features of the original notation, is less labour intensive (see Potter and Wetherell, 1986, for further discussion). In addition, only those aspects of the conversations recorded which related (directly or indirectly) to the research topic (i.e. psychiatric medication) were selected for transcription.

4.4.2 Strategies for validating findings

"The language of themes emerging can be misinterpreted to mean that themes reside in the data, and if we just look hard enough they will emerge like Venus on the halfshell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them"

(Ely et al 1997, pp. 205 – 206).

In order to explore how the validity of the research can be addressed, it is necessary to ask what criteria are appropriate for judging the goodness or quality of an inquiry which adopts a social constructionist paradigm? focusing on how the role of the researcher influences interpretation of data.

This has been the subject of much discussion in the qualitative methodology literature.

According to Guba and Lincoln (1998), there is a need to explore the authenticity of the research project. That is the creation of a sophisticated, but temporary construction of what is considered true by participants. Guba and Lincoln (1998) specify the concepts of; *ontological authenticity* (creates a more sophisticated construction of the phenomenon being studied); *educative authenticity* (leads to improved understandings of constructions); *fairness* (or represents a range of perspectives in the construction) and *catalytic and tactical authenticity* (stimulates to action and empowering action) (ibid, p.213).

A number of features of the research design of this thesis support the authenticity of the construction of psychiatric medication management practice and add credibility to the project. For example, the continued emphasis on participation from both service users and practitioners, via the creation of the advisory group, as co researchers and in the collaborative analysis process ensures that the research process remains sensitive to the differing realities presented in the research and consequently presents a high level of credibility.

In addition, as Seale (1999) notes below, the incorporation of different types of data also informs an authentic construction.

'theory generated from just one kind of data never fits or works as well as theory generated from diverse slices of data on the same category'

(Seale, 1999, p. 55)

As such, the incorporation of differing stakeholders, differing data collection methods and differing analytical approaches enables a sophisticated construction of psychiatric medication management to emerge in this thesis.

In addition, the following best practice advice illustrated in the bullet points below has been followed in the approach to building knowledge in this thesis:

- *Credibility and the importance of fitting the data. Here the need to write an explicit clear and comprehensive account of why phenomena have been labelled and categorized in particular ways*
- *Reflexivity: the role of the researcher needs to be acknowledged.*
- *Documentation*

- *Sensitivity to negotiated realities. The researcher needs to attend to the ways in which the research is interpreted by the participants who generated the data in the first place.*
- *Transferability. Explore the extent to which the study may, or may not, have applicability beyond the specific context within which the data were generated, the researcher should report the contextual feature of the study in full.*

(Henwood and Pidgeon, 1992, pp. 150-151).

Many authors have suggested that member validation is one of the most crucial techniques for establishing credibility of the data (Seale, 1999; Guba and Lincoln, 1995). However this is not to suggest that through the use of such techniques alone, a true or valid picture in of itself emerges, but instead suggests that such techniques are potential aids to a “*deeper and more layered understanding, rather than final adjudications of the truth*” (Seale, 1999, p. 99).

The use of co researchers during the analyses phases thus supports the validation process. Also, the use of a research diary and reflective components of this thesis strengthens the authenticity and documentation of the analysis (Munn Giddings and Winter, 2013). While a structured approach to diary writing was not ensued through the research process, I found keeping a reflective writing log especially helpful way of documenting learning and reflection on the collaborative aspects of the projects. This was also highly useful during the analytical phases, where I was able to refer back to earlier notes and build a defensible account for the analytical decisions made over time, both and as a way of documenting contributions from the collaborative analysis sessions. An added component of the research process which added rigour and authenticity was the transcription of the collaborative analysis meetings³⁸. By adopting this approach I was able to return to the content of these meetings and compare themes emergent from the group meetings to the initial thematic analysis I had already undertaken on the transcripts.

Finally the supervisory team maintained a close 'eye' on both the analytical process and thematic findings, probing both the sensitivity to realities the findings represented, as well as the transferability and credibility of the analytical process. These validation components of the research design ensured that a multi layered and rich conceptualisation of medication management emerged.

³⁸ Collaborative analysis meetings of an interview transcript were later transcribed and coded using N Vivo.

A final aspect to consider concerns ensuring the sensitivity of the findings to negotiated realities, as mentioned above. The participatory components and ethos of the study ensured that everyday realities and experiential knowledge of people receiving mental health services remained at the fore of the knowledge production processes in this project³⁹. It could be argued therefore, that less emphasis has been placed on ensuring the data is sensitive to the negotiated realities of the practitioner groups. However, the dissemination phase to this research, added credibility and sensitivity of the data to the practitioner perspective.

Dissemination and reflection towards change

The advisory group (and myself) presented emergent findings to different audiences. As a group we presented to:

practitioners within the community mental health team, where the study took place
the service user and carer researcher meeting within the local NHS Foundation Trust
the Research into Recovery network, at the Institute of Psychiatry, London
the academic community within Anglia Ruskin University.

These presentations were planned as a group and an equal spread of involvement was observed. For the practitioner presentation (bullet one, above), a particular emphasis was placed on reflection and discussion. This both allowed for the authenticity of the data to be explored with practitioners and also allowed reflection about current practice, with the aim of promoting change.

In addition, I independently have presented findings to the international academic conference, ENMESH, Verona (2013), the ShiMMe conference, Cambridge (2014), and I am in the process of writing for articles for publication in books and academic publications (Kaminskiy, Ramon and Morant, 2013; Kaminskiy, *(submitted)*).

4.5 Ethical Considerations

The research received full NHS ethical approval (Hertfordshire REC, December 2010). Please see appendix VI.

³⁹ While a CPN was a member of the advisory group and collaborative analysis, the remainder of the groups comprised of service users and a carer.

The methodology adopted (social constructionist research paradigm, participatory methodology) is associated with certain ethical considerations being less, while others becoming more prominent, than in traditional designs. For example, the methodology adopted for this study provided an increased incentive towards open and honest dialogue, revealing sophisticated constructions, and therefore safeguarded against problems of deception. However there were other ethical considerations which became more prominent. Confidentiality and anonymity of data was particularly important. Following standard good practice, personal references were removed in the transcription process and quotes used from interviews were not identifiable. In addition personal data (such as names and contact details) were kept securely and separately from the research data obtained. Nevertheless the close personal collaboration in data collection and analysis, required by the methodology, did at times produce specific considerations of confidentiality and anonymity. For example, one co researcher had previously received services from the team where the study was being conducted. It was therefore necessary to ensure that the co interviewer and interview participant were unknown to each other. In addition, during the collaborative analysis phase, it was important to ensure that transcripts did not unwittingly make identifiable references to practitioners, or other service users, whom co researchers may have had personal relationships with. These reflections are referred to in the research diary excerpts (see appendix II).

Risks and burdens to the research participants were present, as with any research. But perhaps more so given the sensitivity of the issues the research explored, and the likely vulnerability of some of the participants. Interviews may have caused distress, raising thoughts of painful and distressing experiences. Indeed a small minority of interviews did require additional sensitivity by the interviewers⁴⁰. To manage this, the interviews were conducted in an environment that was comfortable for the participant and they had the option of bringing along a supporter to stay with them during the interview. In situations where a participant became upset, I or a co researcher used strategies to deal with the situation, by acknowledging their distress and the causes of it, giving thanks for raising a difficult issue, offering to discuss it further with a trusted individual following the interview, and suggesting another question or topic which the participant was more comfortable with. The researcher reminded participants that they were free to withdraw, or have a break, at any time. In addition, the researcher offered all participants, including professional staff the opportunity for a debriefing.

⁴⁰ See the relevant research diary excerpts in appendix II.

However it should be noted that overall, the interviews were overwhelmingly received positively by participants. Many participants were keen to share difficulties or describe examples of success and appreciated the opportunity to participate. Others wanted to understand what may prevent or enhance greater involvement. Many practitioners and service users commented on the positive impact of the research interview on being able to reflect on either their own professional practice, or how to best utilise the services they received. This was a hugely rewarding aspect of the research for me personally. This is well illustrated by an example. During the recruitment process for phase two, I called Holly, a service user who had participated in phase one. She explained that she was no longer able to assist with the research as she had been discharged from secondary care services. I congratulated her and she reflected that soon after the research interview, she had further considered how she wanted to approach future meetings with her psychiatrist. She said that being involved in the research interview had assisted in her taking back control and feeling able to exert her opinion and preferences. She explained that shortly after the research interview she had a meeting with her psychiatrist and that at this meeting she was able to state how she would prefer to participate in the decisions concerning her medication. Shortly after the meeting, Holly and the psychiatrist jointly agreed that discharge from the team was appropriate.

The research process may also have resulted in disclosures from participants that have ethical and professional implications, for example 'dangerous' practice, or possible harm to others. Participants were made fully aware of the limits to confidentiality and the steps the researcher would have to take should such information be disclosed or uncovered. The information was clearly set out in the participant information sheets and consent forms and again at the time of the interviews.

The risks and burdens to the researchers themselves should also be acknowledged. Formal support networks were available via three PhD supervisors and other informal support was also present. I also provided additional support to co researchers on a one to one basis. It was stressed that co researchers may choose to withdraw from the research process at any time, without any repercussions. The debriefing session following the interview allowed initial reflections to be explored, as well as assisting with the preliminary phases of analysis of the data.

4.6. Chapter summary

In summary, this study adopts a social constructionist research framework, with a strong focus on participatory values. It is an exploratory study. The participatory values and components, in addition to the incorporation of different stakeholder group perspectives has allowed for a comprehensive and rich understanding of the key concepts in this thesis to emerge.

There were two phases to the data collection process (a research interview and digitally recorded meeting) exploring in depth the research questions set out in the literature review chapter. A qualitative approach to data collection and data analytical methods has been employed with the aim of building theory in this under researched area. The methodological decisions have been made to enhance the knowledge produced from this thesis and enable fresh insights into psychiatric medication management practice.

Chapter Five. Thematic findings from interviews with service users

Chapter Outline.

This chapter presents the thematic findings from research interviews undertaken with service users, in phase one of the data collection process. Findings are presented at three levels analysis: the interaction, the relationship, and the system. A summary of the commonalities and areas of difference in the findings are provided in section 5.6. Later chapters explore the findings from practitioner interviews and recorded meetings from phase two.

5.1. Introduction - Three levels of conceptualisation

The emergent themes are presented at three levels of conceptualisation: the interaction, the relationship, and the system. This is represented as an 'onion' diagram, shown in Figure 11 below, fitting with the conceptual framework presented in the theory chapter.

The decision to incorporate a three layered approach was made following the initial data driven theme building process⁴¹. I decided it was important to maintain consistency throughout presentation of themes for the different stakeholder groups, maintaining a coherent flow and allowing for more structured comparisons between the stakeholder groups to be made. I was also influenced by my involvement in the writing of an article during this time period which adopted a three level framework in conceptualising shared decision making (Morant, Kaminskiy and Ramon, in preparation). In addition, the conceptual framework developed for the thesis also influenced the final decision to adopt a multi layered approach. This was based on previous models of power (e.g. Brosnan, 2012; Gaventa, 2006, Lukes, 2005) and more general conceptualisations of reality (e.g. Archer, 1995). It is especially relevant in representations of complexity.

In summary, after initial themes were built from the interview data, a decision was taken to adopt a levels structure in presentation of themes, consistent with the conceptual framework adopted for the thesis. However, this is of illustrative use only. Themes are presented for each stakeholder group separately (service users, CPN, Psychiatrist. To

⁴¹ see appendix II for relevant research diary entries

assist this process, a summary section is included, emphasising the commonalities and differences within each stakeholder group.

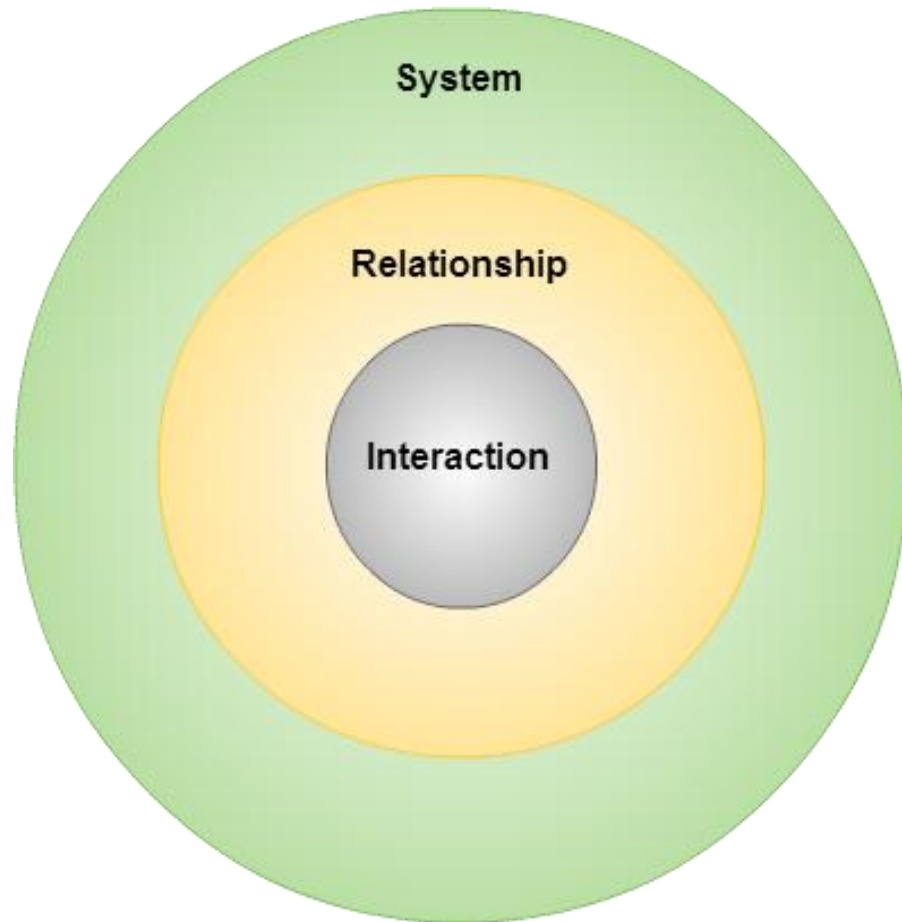


Figure 11. Three levels of analysis

5.2. Participant information

A brief summary of background information for the service user participants (n=15) is presented in table 4, below. Information was 'current' at the time of the research interview. All names are pseudonyms⁴². As can be seen from the table, all participants were in receipt of psychiatric medication.⁴³ All, except one, were in receipt of anti depressants, and four were being prescribed anti psychotic medication. Other types of psychiatric medication being prescribed to participants included mood stabilisers (n=2) and sleeping tablets (n=1). 6 out of 13 were in receipt of two or more types of psychiatric medication. The mean age of participants was 36 years old and 9 out of 15 were female. All participants were receiving services from one community mental health team (the same care pathway) within the local NHS foundation trust (see section 4.3.1) and most were recruited from the Cambridge area (n=12). However two interviews took place in

⁴² Chosen by myself as chief investigator

⁴³ For two participants, medication related information was not recorded

Huntingdon and one took place in Peterborough. Interviews lasted between 30 minutes – 1 hour. Service user co researchers were interviewers in all but three interviews (where I was the sole interviewer⁴⁴).

⁴⁴ Due to feasibility reasons

Participant name	Age	Gender	Class/type of medication currently prescribed	Name of medication, if known	Also known as	Approx. time in pathway (CMHT)	Length of time taking psychiatric medication or since medication changed	Discusses medication with..
Natasha	31	F	Anti depressants	Unknown	SU1	Unknown	Six months taking current medication	CPN, GP
Holly	36	F	Anti depressants Mood stabiliser (for pain)	Trepidone, 200 mg Efexor (or known as Venlafaxine), 300 mg. Also Gabapentin for pain	SU2	Unknown	Taken psychiatric medication on and off since 19 years old. (17 years approx)	Clinical Psychologist, GP
Carrie	38	F	Anti depressants and an anti psychotic	Fluoxetine, Mirtazapine, tryptophan, Aripiprazole	SU3	Over 12 months	Taken psychiatric medication on and off for around 10 years. Most recent change 4 months ago	Psychiatrist, GP, Social worker
Carl	28	M	Anti depressant		SU4	Unknown	Just over a year	GP, CPN, Psychiatrist
Noel	47	M	Anti psychotics + anti depressant	Haloperidol, Amitriptyline, Risperidone, Depixol	SU5	Unknown	Since 1981.	Psychiatrist, CPN, Social Worker
Ziggy	34	F	Anti depressant	Amitriptyline	SU6	12 months	2 months since new medication	CPN, Psychiatrist, GP
Linda	22	F	Anti depressant	Venlafaxine	SU7	Unknown	2 months since new medication	Psychiatrist, GP, CPN
Terry	31	M	Atypical anti psychotic	Clozapine 400 mg	SU8	Unknown	2 years. Reduction in dose 9 months ago	CPN, Psychiatrist
David	23	M	Unknown	Unknown	SU9	4-5 months	4-5 months	Psychiatrist, CPN
Lara	42	F	Anti depressant	Venlafaxine	SU10	Unknown	2 weeks since new medication	GP, Psychiatrist
Peter	50	M	Unknown	Unknown	SU11	Unknown	Unknown	GP
Andrew	49	M	Anti depressant	Unknown	SU12	Unknown	Since 2010	Psychiatrist, GP
Lizzy	54	F	Anti depressant, mood stabiliser	Venlafaxine, Lithium (1000mg)	SU13	Unknown	Venlafaxine: Unknown. Lithium - 6 years since dose changed. Total 10 - 15 years been taking Lithium	CPN, Psychiatrist
Casey	28	F	Anti depressants Sleeping tablets	Fluoxetine, (60 milligrams) mirtazapine (200 milligrams), sleeping tablet	SU14	Unknown	Has been taking psychiatric medication for approximately 2 and a half years	GP, Psychiatrist, nurse (GP)
Rosie	24	F	Anti depressant Anti psychotic	Venlafaxine, Abilify (Aripiprazole)	SU15	Unknown	Abilify changed recently but has been prescribed anti depressants for 8 years	Psychiatrist

Table 4. Service user participant background information.

5.3. Service users - themes at the interaction level

5.3.1. Being ill as a barrier

The vast majority of service users discussed finding it more difficult to be involved in decisions when in crisis or during periods of illness. In particular, cognitive impairments in concentration, memory and motivation were seen as problematic for processing information and weighing up the pros and cons of medication options. In addition, distress during periods of crisis was mentioned as impacting feelings of being able to fully participate and communicate effectively in the decision making process.

***Carrie:** I think when I was particularly ill, I found the meetings very difficult, I didn't know what to say, I really didn't know how to express how I was feeling.*

***Lara:** When I first turned up at the GPs, I wasn't feeling very well at all, so um, it was actually physically hard for me to have a conversation, communicate and understand what was being said to me really.*

... Well again it's a funny thing because of the nature of the illness, the exchange of information is difficult, because you send me off with 6 or 8 names of drugs and tell me to do research and because I can't really read when I'm ill.... because my brain is not processing information properly its very it's like confused skimming and there's not a lot that you can do about that, you can provide all the information in the world but can I take it in, do you know what I mean?

Valuing guidance in a crisis - A dilemma?

During these more difficult times, most participants discussed valuing increased guidance from a practitioner. For some participants, receiving more directive guidance was positively valued. For example, Carl's quote below describes an unsuccessful meeting with his psychiatrist. He refers to not being well enough to ask more questions and describes wanting to be led by the psychiatrist. Other participants refer to the dilemma which emerges during these more difficult times. Holly refers to strongly valuing being involved and taking ownership over decisions about psychiatric medication, but feels that, at times, she is unable to. Importantly, being treated as a person, respect and longer term partnerships were seen to facilitate the problems of not being involved in the short term. These issues are explored further in the 'relationships level' section below.

***Carl:** Um, I think if I'd been in a better place mentally at that time I might have pulled up some questions, um but given how I was at the time, um I don't think I could have done much more because I was looking to be informed by her [the psychiatrist] as much as anything and, you know, that didn't really happen at that point in time*

Holly: Yeah, it's kind of strange when you're really unwell, I feel very helpless because I can't even get out of the house by myself. And I find it very difficult to just be told what to do, I don't deal with authority, but on the other hand, I'm so ill that I don't really have a choice, but I find it uncomfortable. When I'm more able to be part of a conversation about it than I'm a lot more comfortable, I tend to open up a bit more I think. I mean, I try to tell whichever doctor and saying everything but sometimes you know, you can be kind of... sometimes you're actually just talking. It's easier when it's more of a partnership with a more experienced person, instead of just a doctor, you know, a knowing person in the relationship.

I: ...what is it that makes it more difficult?

Holly: Either, when I'm kind of unable to do much about it myself, that I'm very grateful that somebody is taking over and telling me what I need, but it just kind of makes me kind of... I really don't like to be just told what to do without being consulted but I know, at those times, I can't, so I know I need it but I don't like it....

...obviously I need someone - whatever I need to get capable. Yeah, sometimes the sad truth you just need someone to treat you but...

5.3.2. Overcoming barriers - Gaining control

Service users strongly valued being informed. In general, receiving a full explanation of options and gaining detailed information about psychiatric medication and associated side effects was related to feelings of increased control. Being given time to digest information and discuss medication options with the practitioner was seen as helpful. Both Holly and Claire refer to how receiving detailed information assists with feelings of being in control, when unwell. Holly's quote follows on from the previous excerpt above.

I: And in those times, when you need someone to, you know, treat you; is there anything that's really important during those periods?

Holly: To explain what they're doing not just, you know... I find some medical people, they tend to assume that if you're depressed or whatever, they assume that you're stupid, it doesn't follow and I like to know why I'm being given... I'm a scientist you know and I want to know all the details and I might not be able to hold on to them at the particular time, I would like it to be explained to me but if I can't handle the explanation I'll say; actually, that's fine, don't worry about it, tell me in a few months, yeah.

Claire: There and then, yeah, because fair enough in a crisis you can't do that, action has to be taken but I just think if I'd been given that information and going through it yourself and having time to discuss it, you're going to understand. I just think you'd feel like you had more control and you know, that might reduce stigma as well about you feeling you know, you can take control of what's going off.

In comparison, not feeling informed was described as a barrier to collaboration in the decision making process and was associated with feelings of helplessness and a lack of control. Participants refer to wanting more discussion about different options.

CO I: *OK. Um yeah um is there a time when you've found it more difficult to be involved in decisions about your medication?*

Rosie: *Yes, actually, the last time that I saw her [the psychiatrist], my medication was increased, and I my mood was low but I didn't really know like, I wanted more options and I thought that it would have been better if I had talked it through with her a bit more about increasing the dose and instead she just increased the dose and that's it, kind of thing.*

CO I: *So she wasn't really giving you lots of options it was just she was making a kind of decision yeah for you really.*

Rosie: *Yeah, yeah*

CO I: *I was just wondering when you said decisions, you're not explained or given the reaction you want; what do you feel when that happens?*

Holly: *Out of control, like I'm being looked down on and you know, when you're depressed, you already think you're useless and a waste of space.*

Under this umbrella of 'gaining control', the following sub themes are presented by participants as important: gaining self management skills; information about medication side effects; language and communication; and finally, but no less importantly, valuing experiential knowledge.

Self management

A large sub group of participants discussed gaining increased understanding of how medication helps them and learning self management skills. In the quote below Carl refers to the learning how and when medication is helpful. Participants also refer to learning from previous experiences of taking or not taking psychiatric medication in an ongoing experiment.

Carl: *yeah, yeah, yeah, just remembering the names of what I'm taking how much I'm taking um and how I feel before and after I take it so that's like how I felt for certain drug, for one drug or another how I felt three hours before I take it, and how I feel three hours after I take it and so on*

Co I: *Very insightful yeah so uh , you've realised what helps and how it helps*

Carl: *Yeah, and so we've tried to within the GP myself, the psychiatrist and CPN we've tried to balance a way to find out when its best to take the drug and when its best not to as it were um, yeah*

Side effects

Receiving information about side effects was seen as particularly important, with the majority of participants mentioning this. Some participants also referred to not always

receiving enough information. Most participants referred to previous negative experiences of psychiatric medication side effects.

Carrie: *I think I've always been fairly involved because of the side effects I've had on other types of medication, so I've always been quite concerned about the potential side effects that I might have, um, so there's always been a discussion about that,*

Andrew: *One thing is that you are never given enough information about the side effects.*

Participants refer to a number of sources and methods for finding out about the side effects of psychiatric medication. Some participants find it helpful to receive information leaflets or sheets via the psychiatrist or pharmacy.

David: *A lot of the information that was provided for me was provided by my psychiatrist and also the chemist as well which was a big help. They gave me a printout ...which I read through myself, so I've got a bit more understanding what the medication is, and what potentially could go wrong with it like side effects etc..*

Other participants mention doing their own research on side effects and this often involves searching the internet.

I: *So, it's just been you researching the side effects and things and; how do you do that?*

Casey: *Pretty much, I just go and have a look on the internet, I have a look in books and have a look on the sheets really.*

However, for a minority, doing their own research on the internet was less helpful, with a handful of participants instead preferring to ask questions of the psychiatrist or GP.

Natasha: *yeah, I don't know, because I know you need to be really careful. I'd rather speak to a doctor than go by what I read on the internet kind of...*

Language and communication

Language and communication formed part of this umbrella theme, with a few participants talking about how body language and using clear and simple language is helpful when in crisis. Being fully informed and receiving a copy of letters was mentioned by Rosie as a helpful tool. More generally, the importance of reinforcing information and increased discussion about psychiatric medication was especially valued by participants.

Linda: *I think when the discussion is very sort of, um, scientific language....but occasionally it has got quite complex and that I just don't understand it, it doesn't mean anything to me....so talking in simpler language and um, sort of describing the effects that it would have, sort of its supposed to um, to level out your mood fluctuations rather than say it will sort of regulate some sort of hormone in your I don't know your cortex or something, sort of it just sort of easier to understand when its described in terms of what it's going to effect, how it's going to affect you, your mood, your feelings, and thoughts should change with the medication rather than its biological role.*

Rosie: *Um, I should write list, but I haven't yet. That would be helpful. Feedback, more feedback on well she sends me a letter of a copy of a report which goes on file. Yeah, I'd like to be more informed and have more time spent explaining what it could do, because there's a lot to talk about when you start taking medication. Like I don't know how long I'm going to be on this medication for? And um, there are some people, there's so much information out there these days that you don't know what the right information and what's the wrong information is, so um, sort of very confusing [laugh]. Just more time. [laugh] would be helpful.*

Valuing experiential knowledge

The vast majority of participants mentioned the importance of feeling listened to and this often related to the theme of being treated like a person and respect (see section 5.4.2). However, a sub group of participants explicitly mentioned the importance of service user experiential knowledge. Service users' having expertise and being treated with value in the conversation increased feelings of control for some participants.

Linda: *Um, I think ideally it should be um, a collaboration between the um, psychiatrist or prescribing doctor and the service user, so there's sort of the knowledge of the different types of medication on the one side and then the service user knows how they are feeling, they know, sort of whether they've got sort of patterns to their moods that sort of certain types of drugs are more able to help with so its sort of a feedback situation, with both of them contributing*

Holly: *He was really great, I've had a lot of psychiatrists, and you know other doctors that you know pronounce from on high and he was very interested in my opinion about medication and how I was doing, which was really nice because you didn't feel like, you know, god, you know, coming out and saying, you will take this, [laugh], it makes you feel more in control when you're not really in control of anything*

5.4. Service users – themes at the relationship level

The vast majority of service users interviewed referred to the facilitating role of a supportive, caring and trusting relationship between the service user and the practitioner. Service users refer to how a therapeutic relationship enables broader collaborative decision making processes. Sub themes at the relationship level comprise: trust and honesty, respect, shared journey and continuity.

5.4.1. Trust and Honesty

The importance of achieving an honest and open dialogue where trust is established was seen as very important, by the majority of service users.

***Carrie:** I think the main thing is to be as honest as possible. I think um it's no good sort of if you are having side effects, it's no good trying to brush over itthe honesty and the trust I think as well, and you know you kind of build up a relationship with somebody and you get to trust them and I've certainly found that with my present consultant.*

***David:** I have to do everything I can to allow myself to get better but if it means I have to trust somebody that I don't know, which is very, very difficult for me to do, then so be it.*

Conversely, within this theme, a breach of trust was seen by some participants as particularly damaging to the ongoing collaborative relationship. The following quotes are Linda and Terry's recollections of a negative meeting.

***Linda:** that was quite difficult as then obviously my parents knew which I hadn't really wanted them to, so But when um, the doctor told my parents the thing there wasn't much I could do....Yeah it came out of the blue really.*

***Terry:** Probably because they didn't really listen to me, like I was annoyed. I mean, it was probably quite a good thing to have my parents come but I said I didn't want them.*

5.4.2. Respect

Another subtheme that emerged at the relationship level refers to respecting each other as people and being treated as a person. This was mentioned by some participants as particularly important during periods of crisis. Feeling pre judged, not being listened to and not being respected in a conversation was mentioned by many participants, when

recollecting negative meetings. However, participants' previous experiences of feeling respected and listened to varied greatly according to the practitioner (see Holly).

Holly: *Treat me like a reasonable person when perhaps I'm not because I will be again..*

Co I: *Do you think there is anything to change this something in the system?*

Holly: *Talking down to patients, even if you're completely crazy, babbling about random stuff, which I have done a couple of times. Treat them as though they are reasonable people because underneath they're probably already going, you know; oh, I'm useless and if they're treated as useless, then you just feel worse. If it's depression then I doesn't know, you know.*

CO I: *But as you said there, you don't get the same reaction out of everyone.*

Holly: *It seems like some of the younger doctors, seem to be more open to treating you like a person while a lot of the older ones, not all of them obviously but they seem to have this; I'm God, you're patient.*

Natasha: *... someone that you trust and that you've seen, rather than it's some specialist that you may have seen sort of once or twice or some psychiatrist that doesn't know anything about you, I don't know,you know, that's still a person however mixed up their head is, they're still a person.*

This theme also relates to respecting each other as people and respect for different opinions. Ziggy's account below refers to a recollection of a positive meeting with her GP when a decision was made about psychiatric medication.

Ziggy: *Um, so firstly there was a good relationship already there. Secondly they made time for me and I mean I didn't even have an appointment I don't expect that normally. Thirdly there was a real respect for my opinion although I think she actually disagrees with some of my opinion she let me get it all off my chest, and um cry and be upset and then she intervened. And she intervened calmly and rationally and slowly, so she brought the mood down, back to a normal one, she pointed out a few things, that I knew had been difficult, so I remembered that, actually medication could be helpful,*

Within this theme a minority of participants emphasise the importance of the practitioner 'going above and beyond' what is expected. This was seen as indicative of a good relationship having been forged. This also related to reference of 'being on the same side'. This is eloquently described in a later excerpt from Ziggy, when describing her relationship with her GP:

Ziggy: *I have a very good relationship with my GP. She is exceptional... She has gone above and beyond the whole time, her home number, her mobile number and she came up to the hospital in June 09 ... so she's always fought my corner as it were.*

5.4.3. Shared journey and continuity

The vast majority of participants placed importance on the concept of walking a shared journey over time in partnership with a practitioner, with familiarity increasing feelings of safety. Different practitioners, including CPNs, Psychiatrists and GPs were referred to and many examples of positive and helpful relationships were mentioned by participants. A supportive, long term relationship with a practitioner was seen as especially important during periods of crisis where participants felt less able to be involved. The practitioner knowing the person and being able to relate to each other was emphasised (see Rosie, below). Hope also formed part of this theme, with growth and recovery over time being mentioned by participants (See Carl and Natasha). This theme was particularly apparent in participants' recollections of positive meetings, which most commonly referred to meetings when there was joint reflection on the service user's recovery journey, receiving feedback on progress over time and the practitioner knowing and listening to the person.

Natasha: *I don't know, I think it's because he [CPN] kept comparing to how I was and how I am. So, you know; look how far you've come, it was all just really positive, rather than; 'okay, you've taken it, well done'. Yeah, it was real; I don't know it just felt like, yeah, I'm not just like another person that you see because you have to. You've remembered things, he'd like give examples of what I wouldn't do before and what I'm doing now, so it was all very...and he was like; 'well done, you know, before you would have stopped and that would have been it but I'm glad you have, you know, I'm really proud of you, you've done this, you're doing so well'....*

I: *Yeah, okay then; so what was it about this meeting that, you know, sticks in your mind, in terms of why it was positive? What was it about this meeting that was really positive for you?*

Natasha: *I think the fact that it was sort of like; okay, actually I'm getting a bit of control and taking the medication, you know, Mark [CPN] could see improvements and saying; okay, maybe we're getting there and maybe everything might be okay, it was sort of a bit of a turning point.*

Carl: *because I felt positive but also because the key thing being she [GP] felt positive and that for me is a big thing because if someone thinks is thinking positively about me and my situation I go 'Oh, I must be good,' and so its almost a placebo effect*

CO I: *Yeah, that's how people work, yeah,*

I: *Can I ask a tiny bit more about that then, so why, for you that meeting sort of stands out as being particularly a positive meeting ?[cross talk]*

Carl: *I felt so good and it was positive for her[GP] and for me because it showed though I know now I had another bad spell after that, but it showed looking back on it now that I can be better, I can get better, and I can at times sometimes in the near future I will be able to lower my medication again which is which means I'm less reliant on that which is a good thing and that's why it was positive now looking back, because it was a sign that I won't be suffering from this for ever, hopefully, that's the point.*

CO I: *So, if it was an ideal world, um, how would you prefer for the decisions to be made about your psychiatric medication? How would you, you know if you were in an ideal world,*

Rosie: *I just wish there was a way of like, I suppose I go in and I would be able to express myself properly, and say, what I think is going on. I'd have more insight into my illness, like completely, and um, she would somehow ask questions that I can really relate to and say yes I've experienced that, or no I haven't. And kind of test me in a way in order to find out about what's going on and um, then give me feedback. And that's all I want really.*

5.5. Service users - themes at the system level

5.5.1. Power

An overarching theme of power was created to encompass themes associated with experience of aspects of the current mental health system that hinder service user involvement. Within the overarching theme of power, there are three distinct subthemes: fear of coercion; diagnosis, labelling and stigma; and doctor-patient asymmetry. Notably, all sub themes were associated with the service user withholding information, feeling scared and being unable to express their opinion. Service users refer to these sub themes as obstacles associated with encounters when there is a lack of openness and honesty (by both service users and practitioners).

Fear of coercion

Fear of coercion and the legal context of compulsory treatment was mentioned by participants as hindering open dialogue. Often this was based on direct previous experience (see Terry). However, even for participants who had not had direct experience of being sectioned or treated against their will under the Mental Health Act, fear of coercion was nevertheless acknowledged as something that prevents shared dialogue (see David). Fear of coercion was directly associated to holding back information in a conversation.

Terry: *...I kept saying I was hearing voices and the home treatment team immediately called a psychiatrist and he said if you keep telling us this, we'll keep you in hospital. So I thought to myself; if I get these things going on in my brain, I won't tell a psychiatrist because I don't want to be in hospital.*

But then, I sort of started to deal with it myself and realised that what's going on in your brain probably isn't real and these people aren't speaking to you telepathically..So, they said that, you know; if you say that to the psychiatrist, you know, you'll end up in hospital!

I: Did that change what you sort of say in these meetings or not a lot?

Terry: No, I'm normally fairly honest actually, to be honest with you but sometimes I think, maybe I shouldn't say that because they'll look at me a bit different and think I'm worse than I am.

Because I think in the past, you can be a bit too honest, yeah.

I: So that's something you've learnt then, you know?

Terry: Try and be as honest as you can but hold back a little bit because you don't want to sort of end up in hospital when you look different to society.

David: Well, whenever I think of psychiatrists, I think that they're paid to get inside my head and control me. Yeah, so at first I built up this barrier and I was basically letting very little information out.

Diagnosis labelling and stigma

Whilst some participants valued greater understanding of their diagnosis, a few participants referred to an over reliance on psychiatric medication as a primary treatment within current mental health services, limiting choice in the decision making process and reducing opportunities for open dialogue (see Noel). Other participants instead referred to feeling labelled and judged by their psychiatric diagnosis, this once again acting as a barrier to engaging in open dialogue and feeling listened to (see Ziggy and David).

I: .. you are saying, that it could happen, that, you know, you 'could be taken off the street', so does that affect how you feel about having a conversation with your psychiatrist.

Noel: yeah, it does do, yeah. That's what I'm saying. I might as well go along with what the psychiatrist is saying and the drugs they are prescribing because there is no alternative, the only alternative is to come off the drugs altogether, become seriously ill, you might feel a little bit more life in your blood streambut yer GP, psychiatrists just look at that in a really really severe way, they

I: Still now, and you think that's the case now?

P: Oh yeah, definitely, yeah.

Ziggy: The negative meeting is one where I feel pre-judged. I feel that somebody is coming in, this may or may not be the case, but they are coming in they've looked at my paperwork, they've made a decision, and then it feels like they are not really listening to what I am saying. And there are some semblances of listening, but it's not really going in because in their mind they've already put a label on me.

David: hence why I didn't talk about it because I thought I was going to be judged, I was going to be labelled, so I shut it off.

Self stigma was also mentioned by a few participants. For Ziggy, being labelled with 'psychosis' was seen as particularly unhelpful. For her, this label represented a personal failure, thereby making conversations about medication more difficult. Holly instead reflects on the wider issues of stigma and discrimination associated with psychiatric labels.

Ziggy: *It was that use of labelling me that I found too much..... because of the labels and distressing episodes that have happened, particularly when I was in hospital when I've been manic um, I approach meetings, although I try to approach them calmly I approach them with underlying fear..... but I couldn't handle the label psychosis.but for people to say those things to me, I found as a huge personal failing, um and so I didn't use to be able to say psychosis*

Holly: *who was a terrible supervisor and said; look, this is what happened, I'm recovering but I'm not better just to let you know and he acted a bit like; I can't really deal with that kind of problem...*

... He seemed really uncomfortable and I thought, surelyThere was like silence around the table and I said; it's fine, it's just depression, it's not a big deal, there are other people in this lab who have it..... So I started talking about it after that because I thought, well this is ridiculous, you know, there's got to be other people here who are having problems, it's insane that people feel that way.

Doctor - patient asymmetry

Another sub theme related to some participants' comments about the unequal power base during the psychiatric encounter; feeling inferior and patronised in the conversation and scared to express their view in the conversation. A minority of participants also talked about presenting a false picture of feeling better to the doctor (See Carrie). This was associated with feelings of failure and wanting to please the doctor. Of note, this theme reappears in the interviews with CPNs, but not psychiatrists (see subsequent chapters). Interestingly, three of the quotes below are taken from the critical incident (negative meeting) component of the interviews (with the exception of Holly).

Holly: *no, I don't work well when I'm obviously not her equal, she has more training but I don't work well when I'm being treated as, you know, an inferior... I'm an intelligent person, ..., a parent and child I suppose is what it feels like ... but they seem to have this; I'm God, you're the patient.*

Lizzy: *Just trying to patronise me. Trying to tell me that he knew better than I knew. I: and then what happened?*

Lizzy *Nothing, he gave me a prescription for something else and I just went.*

Andrew: *It was the doctor. His style, his attitude really. He just decided the dose, there was no discussion. It is all about their style I suppose.*

Natasha: *I felt like I was being attacked and I don't know, it was like I was coming to them for help, it just felt like I was just being attacked and judged and sort of looked*

down on and it just made me feel really uncomfortable, upset. The fact that I was too scared to say anything, it was, you know, just horrible, it made me feel even worse

Carrie *..I think I got to the point where I almost felt as if it was my fault that I wasn't getting better so there was a part of me, I desperately wanted to come into the meeting and say, yes, everything's getting better things are great, this medication worked and time and time again, it just didn't happen so I found those conversations quite difficult.... I was scared of saying anything.*

5.5.2 Multi disciplinary working

Finally, at the system level of analysis, a few service users referred to how having input from multiple stakeholders impacts decision making. In table 3 (section 5.1), it can be seen that most participants (n=13) had contact with multiple practitioners regarding their psychiatric medication.

For some participants, disagreement between professionals was mentioned, but this was not necessarily seen as impeding the conversation. For some service users multiple opinions were seen as a positive experience, where new ideas or solutions were presented or discussed (See Carl, Carrie). However, for other participants, it was seen to create more confusion in the conversation, especially when relationships with practitioners were not established (See Linda).

Carl: *Yep, OK, I think because within the medical team which looks after me, they partly disagree on the levels of medication, how much I should be taking, or when. Especially maybe um about 6 months ago, maybe there was an argument that the medication I take in the evening I should be taking some in the morning and so on, and kind of, that way, there was a disagreement. My doctor So-and-so, thought I should be taking another ...um but because I met with all them on a regular basis as much as possible, um I was able to keep up to date information, so they were able to come to an overall eventual decision basically.*

I: *Oh, so that took some work on your part?*

Carl: *Yeah, it took some work on my part as much as anything*

Carrie: *we've tried all these medications, we've tried various treatments, therapies and I felt that things were never going to get any better, um, but um, so at that point [pause 2 secs] I was sent for a second opinion and for a fresh pair of eyes sort of helped.*

Linda: *There was the doctor from Fulbourn I'd only met once, and that was for quite a difficult session, so I didn't feel particularly comfortable. And the doctor from my GP surgery, I'd never had an appointment with her, I'd only been introduced to her very briefly, so I didn't really feel that she had anything to contribute, that there was*

any point of her being there. It was just another person when its already quite difficult to express exactly how you're feeling.

5.6. Service Users – Commonalities and Differences

Commonalities across interviews with service users are presented in this section, followed by an examination of differences that emerged between service user interviews.

5.6.1. Commonalities across interviews

In appendix V, the N Vivo coding framework is presented showing themes by number of coded references. This provides an indication of the frequency in which themes emerged from the data. There are a few themes which emerged strongly in the interviews with service users. That is, they were mentioned frequently by participants, with a high level of consensus.

The most commonly occurring theme is coded under the 'barrier' heading, and refers to the theme presented at the interaction level of analysis - '*being ill as a barrier*' (See S. 5.3.1). This theme refers to problems of being ill hindering how participants feel able to be involved. In particular, participants discuss cognitive impairments of concentration and memory, as well as a lack of energy and motivation, as particularly problematic for both feeling informed and processing information about psychiatric medication. In addition, during periods of distress service users found it more difficult to fully express themselves in meetings. Thus, in summary, a key barrier for service users surrounds difficulties of involvement during periods of crisis. Importantly, most service users value increased guidance during these more difficult times, acknowledging that they are less able to take control. For a sub group of participants, however, this reduction of control also represents a particular challenge or dilemma. These participants strongly value control over decisions about psychiatric medication, yet, at times, feel unable to assert this control. For other participants, this dilemma was less apparent, instead referring to feeling comfortable with the prescriber taking a leading role⁴⁵.

Another commonly occurring theme at the interaction level concerned gaining knowledge and information seeking⁴⁵. This theme was mentioned in relation to both facilitators of

⁴⁵ See 'areas of difference across interviews' below

and barriers to (for an absence of information) SDM. In particular, service users strongly value receiving full information concerning side effects, many having previously experienced negative associated effects of psychiatric medication. The provision of this information was associated with feelings of enhanced control and being able to more fully weigh up the pros and cons of psychiatric medication options. This theme also emerged in participants' descriptions of meetings (the critical incident component of the interview).

The vast majority of participants mentioned themes at the relationship level of analysis (section 5.4). Establishing trust, feeling listened to, being treated with respect and walking the journey together in a longer term supportive relationship with a practitioner was described as an important enabler for collaborative decision making. In addition, the vast majority of participants' descriptions of positive meetings⁴⁶ related to these themes. Feeling supported and receiving feedback from a practitioner, as part of a longer term therapeutic relationship, was particularly apparent in the descriptions.

At the structural level of analysis, feeling labelled, pre judged and patronised is frequently mentioned by participants as a barrier to collaborative dialogue, suggestive of more insidious challenges to SDM being present.

5.6.2. Areas of difference across interviews

Key areas of difference across the interviews with service users centre on levels of ownership over decisions concerning psychiatric medication. This diversity is present for both participants' previous experiences of being involved (from feeling very involved through to feelings of not being involved at all), and for participants' expressed preferences towards different models of decision making⁴⁷.

These differences are illustrated in table 5 below, which identifies how participants' respond to questions that explore both how decisions are made in practice (Question: *In general, who usually makes the decision about your psychiatric medication?*) and participants preferred level of participation (Question: *In an ideal world, how would decisions be made?*).

⁴⁷ See chapter two for description of different decision making models

Question responses concerning level of involvement	Who usually makes decisions about psychiatric medication? (*) (**)	In an ideal world, how would decisions be made about psychiatric medication? (*)(**)
The psychiatrist/prescribing doctor take the lead on decisions	Carl, Rosie, Andrew, Casey, Terry, Noel, Ziggy, David	Rosie, Lizzy, Carl,
Joint decision / collaborative	Linda, Holly, Terry, Noel, Ziggy	Lara, Ziggy, Linda, Holly, Casey, Carl, Terry, David
The service user takes the lead on decisions	Natasha, Lara, Lizzy, Carrie, David	Ziggy, Lara

(*) Some participants are recorded in multiple categories, reflecting diversity of response within an interview

(**) Where the response was unclear or did not fit within a category, the participant response is not recorded.

Table 5. Participant responses for perceived and preferred levels of involvement.

As can be seen from this table there is a fairly equal spread in responses in perceived levels of involvement over decision about psychiatric medication (shown in the first column). In other words, for some participants, the psychiatrist is seen to lead the decision making process, and for others, the service user perceives that they hold ownership over decisions concerning psychiatric medication.

There were also differences between participants' preferences of participation (as shown in the second column). This was often related to what participants viewed the practitioner (and their own) role to be in an ideal world. While there was a spread of response observed, the majority of participants discuss their preference for a shared dialogue, feeling involved and forming a longer term partnership in the decision making process. This is illustrated in Holly's quote, below. However a sub group of participants instead valued a paternalistic approach where the practitioner (and in particular, the psychiatrist) perform the role of the expert, leading the decision making process. For these participants, the service user viewed their own role as providing relevant information. This is illustrated by the quote from Carl, below.

Finally, another smaller sub group of participants describe a preference for a more informed model of decision making. That is, the role of psychiatrist or practitioner as someone who has expertise in medication, but who has no say over the decision. This view is illustrated in Lara's quote below. However to note, whilst Lara refers to a highly

informed dialogue of being given ownership of the decision (and the psychiatrist taking an advisor role), later in her transcript Lara also refers to valuing the opinion (or gut feeling) of the practitioner. This is, as oppose, to just receiving the relevant information to weigh up independently. Thus, even within the same interview, there was some degree of variability, perhaps indicating that such preferences towards involvement may vary according to the situation.

Carl: my **psychiatrist .. she, as leader of the project that is me**, , she is very much more led by my GP, ..my GP and her exchange notes ..she's kept up to date with any relevant information regarding my medication. They take on board what I say, but ... she is looking at the longer term,

Co I: Great insight into all this, yeah [joint laugh] isn't it, are different options presented, so would you say you have many, uh, much information about all of this, so have you explored all that can be done or do you leave some to them? or [cross talk]

Carl: I leave it partly to them. I have looked at other ways of dealing with..my illness, which would down to me, which is based on physical exercise and general wellbeing in terms of certain environments. ...[On] the medication side **I will generally leave up to them but I will give as much information as I can because they're the ones who spent eight years or so learning you know learning how to deal with the illnesses, I'm only the patient so I try to give as much information to them as possible...**

CO I: So in an ideal world, how would you prefer for decisions to be made about your psychiatric medication? Stay the same, change, maybe a new way?

Carl: I think this way is a good way.

Holly: As time has gone on it is much **more of a partnership, very much more of a conversation**. So, you know, 'how's that working', 'oh its pretty good but I don't know if its strong enough I am still having trouble sleeping', 'Oh really, well we could put it up a bit more -do you want to go up 50 or 100', 'maybe 50 because it zones me out so much'.... so it was much more conversational. Like obviously he's the expert, I don't know that much about drugs, **but it felt really nice to be able to have a conversation with a psychiatrist rather than just 'OK, yes sir'**

Lara: I went and did what research I could about it and chose one and he[the psychiatrist] was like, 'OK that's fine',

I: Was any kind of preference presented to you then? You know 'well this is possibly what I think might be preferable?'

Lara: Not really, not at that point, I mean he [the psychiatrist] suggested there were two options - either I could go on anti psychotics right away and keep taking the anti depressant I was already on, or change anti depressant and not take the anti psychotic.

I: Yeah, I'm quite interested in talking about this,. You said you were given these 7 or 8 options, but before that there was some sort of conversation about whether to come off the medication you were on, or to add a anti psychotic, -these two, kind of, options.

Lara: And again, Dr Percy presented them to me as, sort of, two ways that we could sort of go forward and you know he sort of said, 'you're getting these symptoms it depends on [you] how well you think you can tolerate these symptoms, or whether you'd rather start taking the anti psychotic and see if that changes the symptoms that you're getting, or just change the anti depressant and see if that kind of takes care of.. So I decided not to take the anti psychotic and to take the SSRI instead.....

I:.....In an ideal world, what would happen?

Lara: Well I think in an ideal world I think the psychiatrist or the person that has more intimate knowledge of psychiatric medication and how they work, um, was able to put, sort of distil that knowledge into a form that was easily understood by the person that was kind of going to be taking the medication,

I: OK

Lara: Um, and allow them to make the decision, based on that information that the psychiatrist has by which I mean not just OK, this is an SSRI etc..... but also I think um, in my experience... most people who work as psychiatrists .. end up having a gut feeling about oh, this person looks like the sort of person who would be helped by x y or z without really having any kind of scientific um it's **more of a hunch thing**, but **I personally would be happy if somebody would kind of share that information with me...**

I:... So presenting their opinion?

Lara: **I would be happy for them to present their opinion** I would not be happy for them to say, you know you have to take this or you know you don't know enough to but I've never really known enough to experience anyone actually do that to me, you know I've had people say to me, you know I'm going to give you this, but I've never felt that I didn't have an input

5.7. Chapter summary

In this chapter, the emergent themes from interviews with service users are presented at three levels of analysis; the interaction, relationship and system. The chapter concludes with a summary of commonalities and differences in the data.

Service users commonly report challenges of feeling involved during periods of crisis, and during these more difficult time value increased guidance. Receiving comprehensive information concerning medication side effects was strongly valued by participants. Themes at the relationship level are apparent in the data, where a longer term trusting relationship is established and knowing the service user is at the fore. The themes of trust and honesty, respect and being treated as a person, as well as a shared journey, are presented. Themes at the system level centre on the barriers of feeling labelled and pre judged in conversations where medication was discussed. Power as an obstacle to SDM is explored, consisting of the sub themes; fear of coercion; diagnosis, labelling and stigma; and doctor - patient asymmetry. An additional theme 'multidisciplinary working' is also described.

Differences between interviews with service user participants also appeared in the analysis. These differences represent a diversity in participants experiences of being involved in decisions about psychiatric medication, as well as differences in participants' preferences towards levels of participation in the decision making process. For some participants preferences were seen to differ according to situation, over time.

The following chapters present findings from interviews with practitioners. This is followed by an exploration of some of the similarities and differences between the emergent themes from each of the three stakeholder groups.

Chapter Six. Thematic findings from interviews with psychiatrists

Chapter outline

This chapter presents thematic findings from interviews with psychiatrists. As with findings from service user interviews (Chapter five), themes are presented at three levels of analysis: the interaction, the relationship, and the system. This is followed by a summary of areas of commonality and difference between interviews with psychiatrists.

6.1 Introduction- Psychiatrist background information

Seven consultant psychiatrists from one CMHT pathway participated in research interviews. Eight consultant psychiatrists were practising in this pathway during the data collection period. One psychiatrist did not respond to an invitation to participate. Interviews lasted between 45 minutes and 1 hr 15 minutes. The majority of participants (5/7) had been working within the pathway for over six months. See table 5 for more details.

Psychiatrist number	Pseudonym	Job title and length of time working in the CMHT pathway (at time of interview). Other background information	Gender
Psychiatrist 1	Dr Loh	Consultant Psychiatrist for over 2 years in this pathway. Qualified as a Consultant a number of years ago and has worked in different mental health teams locally.	M
Psychiatrist 2	Dr Percy	Consultant Psychiatrist in this pathway for approximately 8 months. Previous role was also community based psychiatry. Relatively newly qualified.	M
Psychiatrist 3	Dr Black	Consultant Psychiatrist in this pathway for approximately one year. Qualified as a consultant a number of years ago and has experience of many parts of MH services locally.	F
Psychiatrist 4	Dr Bloggs	Has acted as a Locum Consultant Psychiatrist in the pathway for approximately 2 months. Previously has worked in many different MH teams and contexts (acute/community) across different parts of the UK.	M
Psychiatrist 5	Dr Kos	Consultant Psychiatrist on specialist register. Unknown length of time in pathway, but has worked in the NHS for a number of years.	F
Psychiatrist 6	Dr White	Consultant psychiatrist in this pathway for 2 years. Number of years experience in other parts of MH service.	F
Psychiatrist 7	Dr Green	Consultant psychiatrist in this pathway for approximately 3 months. Newly qualified.	F

Table 6. Background information for Psychiatrist interviews.

6.2. Psychiatrists – themes at the interaction level

6.2.1. Service User Ownership

The majority of psychiatrists stressed the importance of the service user having ownership of the decision. Psychiatrists viewed themselves as advisors to the process, presenting information and options in a balanced way and encouraging the service user to take increased control in the decision making process, learning skills of self management (See Dr Percy, Dr White and Dr Black, below). Sub themes under this heading include; the importance of allowing time for decisions and; the dilemma of false compliance.

Dr Percy: uh [exhales] I would see it as how involved should we be in that decision making, because its theirs, if I'm the patient, I'm the person taking the medication, I'm the one who's going to feel drowsy not the doctor. So it's my decision,

*it's my life, its affecting me, um an obviously yes, if I have trust in the doctor then I will want to you know get their views about it, **but primarily that decision making is the patients responsibility, unless they are not able to make that decision or they make it clear that they don't want to make that decisions.***

***Dr White:** I take a very clear approach that I can't force anybody to take treatment, and I see it as **my role to present the evidence for and against, and to come to dialogue and understanding.** If some of my recommendations are about the options of treatment and maybe I would, sort of, ere on the side of possibly most helpful for you to understand what their hesitations are, to see whether or not there is something that one can do about that. But sometimes it's just a difference of opinion and I guess I feel very strongly that unless people are convinced about the usefulness of medication I'm not there to give it to them every day and I'm not there and it's their life and actually very much their decision.*

Dr Black:** Well, **they are in charge of it completely. They come to me as an expert of medication.** My job is to put for them my best opinion and to give them the tools to make a cost benefit analysis on that and to be able to choose to do it or not to do it.

Allowing time for a decision

The importance of allowing time for decision making and for the pros and cons to be fully considered was emphasised by a number of psychiatrists as a crucial aspect of the service user gaining increased ownership over the decision.

***Dr Percy:** I usually ask them not to make any immediate decision but say that, you know, these are the range of options, um actually if they use the internet then I give them the links for each of them to try and explore, talk to other people they want to, talk to and write down what the possible options are, a brief overview, what the pros and cons are with each of them, and then either tell them, if you think you want to pursue any of these then ring back and we'll talk further about this or, if you say that you don't want to that's fine, but these are the pros and cons of using medication versus not using medication, that's your decision.*

The dilemma of false compliance

Some psychiatrists however referred to a dilemma that emerges from being seen as an expert or advisor in the medication management process. On the one hand, whilst genuinely valuing the service user gaining increased control and ownership of the process, psychiatrists also feared that, on occasion, service users may paint a picture of false compliance or agreement, in order to preserve the status quo and save face in the encounter. This is presented eloquently by Dr Black.

Dr Black: *I cannot be absolutely sure that people are being absolutely honest with me and would say, I don't like the sound of that, [laugh] I don't want to take it, I mean some of them are going to say, 'I got out of there and all she said was I ought to go to the GP to get that stuff. I don't want it, but I've got of here without losing face'. 'Um, I'll have to think about how I face her again when I haven't taken any of it', and that's the problem .. I don't want people to go away and not take the drug because they can't face me, but they will, some of them.*

6.2.2. Presenting information

All psychiatrists referred to the importance of providing relevant information to service users about medication choices, giving details of side effects, as well as consulting with the service user about the pros and cons of different options. However, the type and amount of information psychiatrists provided varied and was dependent upon a number of factors, suggestive of a complex interactional process. This theme consists of sub themes; side effects; helpful tools; and giving the service user choice.

Side effects

All psychiatrists stressed the importance of presenting information to service users about common side effects. However most psychiatrists referred to not always being able to give detailed information on side effects as part of the meeting. Instead, referring service users to printed leaflets, or recommended resources on the internet was a common experience for psychiatrists.

Dr Percy: *I think I'd usually say the commonest side effects that other people have mentioned to me about medication, but I usually tell them to look it up on the leaflet I provide, or the internet, because there's no way I can go through all the side effects and I don't know which of the side effects might be important to them. Which is why I think it is important for them to look it up. Also I explain to them that there are some side effects mentioned that might not be that common, so the frequency with which each of those happen. So if they want to talk about any of those concerns they have or talk to me about those issues, they can.*

Whilst, in general, psychiatrists did not think they would deliberately hold information back on certain side effects, there was acknowledgement by some participants that the level of information provided did vary, depending on the service user (see Dr Black's quote). One psychiatrist (Dr Loh) also referred to being less comfortable talking about sexual side effects and the longer term side effects associated with antipsychotic use.

Dr Loh: *I think I'm quite bad at telling people about sexual side effects ...and I'm probably not great about telling people about possible longer term side effects about things and particularly anti psychotics I suppose*

Dr Black: *but I'm afraid it is a bit of a judgement call all the time, so I may and maybe the most intelligent people still get more information than the people on the other hand, I can't pretend that I'm not influenced by that if people keep asking me questions, then I'll answer them, if people say, whatever you say doctor, then I'll say less, it's human nature.*

Helpful tools

A few psychiatrists described helpful tools they use to assist the involvement of service users in decisions about psychiatric medication. One psychiatrist discussed the usefulness of service users preparing for meetings and bringing along a friend for support. Two other participants referred to providing a written plan and sharing this with the service user, as helpful. Sending a copy of a letter to the service user following the meeting, detailing the outcomes and points from the meeting, was also seen to assist collaboration with the service user.

Dr Black: *and what I found was it was really helpful for them to have the medication written clearly, and how they were going to use it, its name, its drug dose, and I wrote that to the GP, but then if I copied it to the patient, they had it too, so they knew what exactly I thought they should be taking, not just what I recommended to the GP.... I found that actually sending the letter to the patient was a very powerful collaborative tool, not perfect, because sometimes I wanted to say things that I didn't want the patient to know about straight away, you know opinion that the patient didn't agree with, so that has modified how I communicate with my GPs.*

Choice

All psychiatrists strongly valued giving the service user choice and the importance of weighing up the pros and cons of different options. However there was acknowledgement that this choice was, at times, limited, based on the psychiatrist's perception of what is deemed most relevant. Participants also referred to presenting a backup plan or a plan 'B' as a common approach. Thus, whilst on the face of it, ideals of providing choice were valued many caveats were described. Instead psychiatrists referred to constructing arguments concerning medication options, thereby limiting the amount of perceived choice service users feel they may have. For example, in Dr Loh's quote below, there is reference to presenting a couple of choices and then using the term 'but' to further guide the discussion.

Dr Loh: I mean the choice maybe a little bit limited so, it maybe, here are a couple of choices but I don't think we should do this one because facts, and you know it may be a kind of limited discussion, but no, I'm quite happy for uh people to have choices. Certainly things get more complicated, what I fairly frequently do is give people choices in advance, so you know, well this is what it's like today but if it's no better with this, these are the options we are looking at.

6.2.3. Service user expectations

A sub group of participants referred to problems associated with some service users having set or pre conceived expectations for a meeting. Having a set agenda and not listening was seen as disruptive to the conversation (see Dr Blogg's quote below). A few psychiatrists also expressed the concern that some service users create pressure for the psychiatrist to fix or offer a definite solution to a problem, thereby encouraging the psychiatrist to adopt a more paternalistic stance (see Dr. White's quote below). Interestingly, both quotes refer to the critical incident component of the interview, where a poignant but negative meeting is described.

Dr White: but it's also I think the sort of decision making power that she, sort of, puts with you and sort of 'tell me what to do, tell me what to take to fix it', and that's a sort of pressure and I suppose my overall view of this is that 'this is not the thing that is going to help you the most', but I think it somehow the inability of me to convey that to her,there is something about the pressure that anxious people put on you to fix it that really makes it very hard to have that conversation.

Dr Bloggs:the first thing she wasn't listening. It's not that she didn't have the capacity to listen,.... I wasn't saying what she wanted to hear.

6.2.4. Being ill as a barrier

Lacking insight

Most participants referred to the problems of engaging in collaborative decision making if a service user was seen to lack insight into their illness. Formation of a joint dialogue and presenting information about psychiatric medication was seen as more difficult in these circumstances. Lack of insight was also related to changing the information that is presented and constructing a different argument to avoid conflict in the encounter. Dr White's quote below mentions the problem of referring directly to the term 'anti psychotic' medication and Dr Loh's first quote emphasises the need to change the focus of a conversation towards other *secondary* symptoms, focussing less on potential long term side effects of the medication. Thus, psychiatrists refer to a relatively sophisticated process of constructing conversations about psychiatric medication when someone is

deemed to lack insight. Dr Loh's second quote, below, is a recollection of a negative meeting (critical incident component of the interview). Here, Dr Loh suggests the service user is very *anxious*, possibly as a way to construct and open the conversation towards a decision about medication, without having to openly explore the service users experiences of his 'brain not working properly'. For this meeting, this change in construction about medication is not well received by the service user, resulting in a lack of shared understanding.

***Dr Loh:** so I guess kind of I guess if someone's psychotic and think being persecuted by the names have got bugs in the house and **then start talking about tablets then people just think you know you haven't grasped the situation** and what you need to be doing is talk to the police...*

*...then a conversation about medication can go a slightly odd way and tend to **focus on symptoms that might be otherwise quite secondary**. So if people are particularly anxious about being chased by MI5- if you enter a conversation about what you might expect from these tablets in terms of getting rid of delusions about being chased by MI5, then it might go extraordinarily badly ...whereas conversations that this might help with your anxiety and your ability to wind down it might help you sleep a bit, might go better and you know it might avoid an admission to hospital and all kind of things and that rather kind of spoils it if you then say, 'oh by the way if you keep taking these for ten years, you might get kind of um problems'*

***Dr Loh:** so it's almost like we end up having kind of **two separate kind of conversations** so I'm having a conversation about you know maybe asking questions trying to feed a bit back, so **it sounds like you're very anxious at the moment and things aren't working well and then he's having a conversation where he holding his head in his hands and saying my brains not working, no one understands**, this is just terrible I just can't possibly go on like this ...*

...there's never quite a meeting of so even when I'm trying to kind of say I understand that things are terrible and you're very anxious and so on then it never, we never, quite meet the conversation which is a bit disconcerting really...

Dr White:** ...they don't necessarily see as part of being ill, and then it becomes quite difficult to involve people um on the same level because you have to walk a fine line between giving information that is correct and factual um but also **if you start talking about this is an anti psychotic drug

...People start saying, but I'm not psychotic and so it's often about a fine line not. It's not about giving the wrong information but giving information that would lead people to consider perhaps the options more carefully

However, whilst the majority of psychiatrists mentioned the problems of involving people when they are deemed to lack insight, one psychiatrist (Dr Kos) emphasises that ultimately the service user has the ownership over the decision about whether or not to

take the medication, and as such lacking insight was not a direct barrier to involvement by this psychiatrist.

I: Are there things that affect the ability to involve service users in the decisions? you know are there situations or um specific things that hinder service users being involved in the process?

Dr. Kos: *I think the only issues are just the capacity.*

I: So, capacity in terms of uh insight the illness, or are we talking capacity to consent sort of?

Dr. Kos. *Capacity to consent, and have a clear understanding, what decision to make, it someone doesn't understand the difference between two medications because doesn't have the capacity, again it hasn't happened to me that will be the case. **It's not about insight, I think if someone hasn't got an insight and I feel that very strongly he suffers from a mental illness he needs to take medication, again it would be a decision made by him if he doesn't want to take, he doesn't take it.***

Periods of crisis as a barrier

Other barriers to service user involvement were described as service users being less able to process information during periods of distress and crisis (see Dr Green, below), although this was mentioned less by participants, as compared to problems of lacking insight. Of note, lacking insight was described as a separate issue to severity of illness by some of the participants, as illustrated in Dr Blogg's quote below.

Dr Green: *The difficulty I sometimes have is when they come to me they're anxious and sometimes their mental state, more often than not, I see people that are depressed and anxious, so they just aren't registering half the things that I tell them in the consultation. So, I can tell them as much information as I like but I don't know how much of it goes in and gets registered.*

I: What factors affect peoples' ability to be fully involved in the decision making process about their psychiatric medication?. Is there anything, and if so, what?.

Dr Bloggs: *[laugh] Yes there's factors. If you're very ill for instance uh somebody who is very agitated somebody who is so psychotic they don't even understand the medication, makes it difficult for you either to discuss at length or for them to understand the information you are passing across.*

..That is one. Even when they're not that ill, their insight is still very important, because there are those of them which see that they are ill, but they don't have any insight into the illness and so they don't want anything to do with you about medications sometimes [laughing]. So insight is very important. The severity of the illness is also very important.

6.3. Psychiatrists - themes at the relationship level

6.3.1. Achieving open dialogue

Psychiatrists valued achieving good rapport, a sense of trust and open and honest dialogue with the service user. This theme was often associated with descriptions positive meetings that stood out for the psychiatrist (the critical incident component of the interview). Here, psychiatrists emphasised the importance of achieving an open, honest and constructive dialogue, where trust has been established. There is little mention of the more caring aspects of the therapeutic relationship, such as listening, supporting or walking the journey together with the service user. Instead there was a focus on the importance of service users being open in conversation, listening to guidance but expressing their opinions/ preferences. The theme consists of sub themes; the importance of honesty, the role of the carer and; having a personalised approach.

The importance of honesty

Many participants emphasised the importance of the service user being able to express their preferences openly. This appeared paramount to the psychiatrists' conceptualisations of a constructive relationship for decision making about psychiatric medication and was associated with the service user taking increased ownership and control over decisions.

***Dr Black:** I thought it was really good that she was able to talk frankly about the pros and cons of the medication and she felt she could say she needed this stuff....Yeah, good rapport, trust, a sense that she could say what she really wanted, she came with her mum, I don't know if that made it more possible, maybe I would need some persuading.*

The role of the carer

Interestingly in the quote above, the carer⁴⁸ is seen as helpful in achieving open dialogue. However, there was acknowledgement from psychiatrists that the role of the carer was highly dependent on the situation. Sometimes the relationship between the carer and service user was seen as helpful for increasing involvement, but at other times it was seen as a hindrance to establishing a honest open dialogue, creating instead more hostility in the conversation.

⁴⁸ The term carer was defined very broadly in interviews, as a 'loved one, friend or family member'

Dr Loh. *..I mean you've got to be aware of how the person how much influence the person has or what their relationship is like, so sometimes, they can be a bit of an ally if someone is not keen on tablets and you think they should be on it, they can be there saying 'this is your doctor, you've got to take them, you cant possibly go on unless you take them', uh, and sometimes that can create a bit of hostility. I suppose, where there needn't be any. So, you know, if I'm trying to get someone to take tablets to improve and they're not terribly for it, then having their spouse also coming on my side it, kind of, makes it more fraught and not particularly helpful so I guess you have to be aware on the effect your discussions are having on the wider situation.*

A personalised approach?

Only one psychiatrist directly mentioned that having a personalised approach and knowing the person, is beneficial for conversations about psychiatric medication. Dr Kos, below, in her description of a positive meeting (in the critical incident component of the interview), refers to the importance of knowing the person, assisting her effectiveness in tailored presentation of information and provision of explanations.

For most psychiatrists, however, there was acknowledgement that building a partnership over time / regular contact was not necessarily present or required⁴⁹.

Dr Kos: *I think that because I know her well I think I can read her well as well I think I know what she means and she is very straight forward and I think I can understand her, I think that's why I was also able to present her with quite balanced argument because I knew what she would respond better yeah, so I think that it might not happen in every case because sometimes I am meeting people who I saw first and I'm not so aware of how they behave or what is the easiest way to explain them things, because some people need a different type of information, or giving different types of examples,*

6.4. Psychiatrists - themes at the system level

6.4.1. Mental Health Act and Fear of Coercion

The Mental Health Act and being treated against a person's will were acknowledged as barriers to involving people in decisions about medication. A minority of psychiatrists mentioned that, at the explicit end of this, compulsory treatment impedes involvement, as consent is not required (See Dr Blogg's quote, below). However within this pathway, the vast majority of psychiatrists highlighted that, in general, compulsory treatment and coercion was not relevant to medication management practice (See Dr Black, below).

⁴⁹ this is explored further in S. 6.4.2 'the changing role of the psychiatrist'

Instead, some psychiatrists interviewed suggested that service users may experience fear, based on previous coercive experiences of the psychiatric system. It is this fear that was seen to prevent honest dialogue (see Dr Loh's quote, below).

Dr Bloggs: *There are times when you don't need to get their consent because they are that ill you just have to say, look this is what you want, ..but in those times, if it is in a different setting, and they are being treated under the mental health act, obviously , again, it depends, for some it's an act for treatment, you still discuss with them as much as possible, but you don't need their consent to start treatment.*

Dr Black: *Well, in the intake and treatment team, where people are competent and people are capable and there is no element of coercion to their management, so they're insightful etc, they are in charge of it [the decision] completely.*

Dr Loh: *He might be a bit scared because the last time he stopped taking it he became quite unwell and ended up in hospital so he might be worried that people will cart him off to hospital if he says he's stopped taking it*

A minority of psychiatrists also acknowledged that, in situations where service users were seen to lack insight or not understand they are ill, different constructions of arguments concerning psychiatric medication may be employed. These scenarios may be more in keeping with ideals of compliance, being manipulative in style. This may serve to avoid overt conflict in the encounter, created by discussion of people's understanding of their symptoms. For example, in the quote below Dr Percy highlights the future possibility of the service user being treated against their will under the Mental Health Act. This leaves little room for further exploration of the service user perspective.

Dr Percy: *you don't think you need to take medication and you don't think that some of the experiences are part of a mental illness, and that's fine but my concern is that if the status quo continues and as you can see, already your parents seem to be really worried, and they seem to be more and more concerned my worry is that if you don't take medication further down the line the possibilities are that you might actually end up in hospital uh against your will.*

In summary, some psychiatrists acknowledged a general fear of coercion indirectly hinders full involvement in decision making about psychiatric medication in this community based team. This may relates to the service user holding back certain information, or result in the psychiatrist constructing and directing conversations, so to avoid conflict in the encounter.

6.4.2. Mental health services structure

The changing role of the psychiatrist

There was widespread recognition that change in structures of mental health services over recent time has influenced decision making for psychiatric medication management. There was reference by five psychiatrists that modern mental health services are now more consultative in operation, with psychiatrists performing the role of an expert advisor in the decision making process. GPs were described as being at the centre of the process, providing continuity of care and having an ongoing relationship with the service user. Psychiatrists in this setting were unlikely to see service users on a regular basis, but more on an as and when basis, depending on the complexity of the decision making process (See Dr Percy and Dr White, below). When questioned about the role of the psychiatrist in the medication management process, all seven psychiatrists referred to medication expertise as being a central part of the psychiatrist role (See Dr Black, below).

Dr Percy: *I mean because of how the mental health services are structured currently, compared to the past, where you would see a patient and would continue to see them for a good length of time, you'd build a relationship and you are overseeing the treatment for a long period of time. From there to now it's moving towards the GP being the centre managing the patients and the consultant psychiatrist providing a sort of consultative model... and there are sort of pros and cons with either. But currently model is one of where you don't see the psychiatrist unless its um, extremely complex, extremely risky.,*

Dr White: *So I have a quite flexible approach but I think often that I have to really see what the added value is that um and the patient has to see what the added value is. Not just my view, it's also what's the patients view, and is there anyone else that could potentially do that just as well?*

Dr Black: *Because actually however much we are supposed to be generic workers, the doctors are kept for the people who want medication and I may disagree with that but that's the way it is at the moment.*

The role of diagnosis.

There was some diversity between psychiatrists' responses regarding the importance of diagnosis for initial decisions about medication. Some psychiatrists emphasised diagnosis and formulation is an important aspect in medication management practice, ensuring from a medical view, the person receives the most appropriate medication. For example Dr

Percy (see quote below) acknowledges that research and evidence base is centred on diagnosis and therefore is a significant factor in the process. A sub group of psychiatrists, however, referred to an overly medicalised or biological perspective as distancing experiential knowledge, and consequently, a problem in medication management practice (See Dr. White's quote below). Overall, most psychiatrists viewed medication as one tool, as part of a bio psycho social understanding of mental illness.

***Dr. Percy.** key role in use of medication in any person who has a mental health problem from a psychiatrist point of view is that it always focuses on diagnosis mainly because all the medications are trialled studied experimented, everything, based on diagnosis, so it's a significant factor, uh in discussing any medication,*

***I:** Do you see yourself as having any difference in style or approach to your colleagues.*

***Dr. White.** I think so, not to everybody, but I've got some colleagues who have got very specific views and I call it biological but I guess who come from a kind of view that um, symptoms can be targeted by medication and that when people keep representing with symptoms then all you need to do is increase the drug and it is about finding the right drug for the right person at the right dose or the combination. I think I see myself less as a, uh, I don't prescribe to that view in psychiatry and I haven't seen it work. Um, so I think I am different from some of them, but I also have colleagues that have very similar views to what I have.*

Psychiatric training

A few participants expressed concern that training for psychiatrists is dominated by an overly medicalised approach (See Dr Green, below). In addition, one psychiatrist referred to the need for junior psychiatrists to have a greater appreciation of the longer term consequences of prescribing. Short term rotations and placements, were seen by this participant, as creating less chance for trainee psychiatrists to see longer term outcomes for service users (See Dr White's quote, below). This was seen as particularly problematic for engaging in collaborative decision making, and adopting a more holistic approach in medication management practice.

***Dr White.** I mean when I was a junior doctor I was much more convinced that maybe drugs could be helpful. I think they still could be helpful, but I've seen probably because I think the difference between being a junior doctor and consultant is that you've got people over a lot longer period of time. So one of the weaknesses of psychiatric training is that you rotate all the time and you don't often see the consequences of your decision making and you also don't see that over time the*

things that make a difference are maybe not the things that you've prescribed and actually the improvement is to do with something very different. Um and also you don't see the consequences of your prescribing habits so you know some medication has got huge consequences for weight and if you're not the one who has to think about that in 2 years then maybe your prescribing is about now here and there, and you don't see the consequences of having to wean people off medication that maybe in the long run wasn't necessarily so helpful, so I think my view has changed over that.

Dr Green: *but I do think as starting off [as a psychiatrist], I think I was a little bit more direct in my recommendations maybe or choice and that may well be because I didn't have the exposure .. and also perhaps there was that very medical approach where you kind of said; this is the drug. You'd still talk about the side effects and everything but I think it was more of a direct recommendation, rather than, you know, being flexible with the patient perhaps, less flexible than I am now I suppose.*

Recovery oriented services

Changes in mental health services towards a recovery oriented approach were also mentioned by some participants. This was associated with a change towards greater service user autonomy and responsibility. However, one psychiatrist questioned the drivers for this change, suggesting they may not necessarily be for patient centred reasons.

Dr Green: *I think it's a measure of everything isn't it? I think we are becoming more recovery focused and recognising the need to give the patient more autonomy and responsibility but, on the other hand, whether that need is being driven by true recognition of the patient's skill, or because we don't now have enough resources and that's why they're coming..... that is the question to be answered.*

Increasing medicalisation of emotions

Of final note in this section, a minority of participants mentioned that changing attitudes and outlook towards mental illness and distress influenced the medication management encounter. The quote below reflects that there has been an increasing trend towards medicalisation of certain behaviours, impacting expectations during the psychiatric encounter ⁵⁰.

⁵⁰ Also see S. 6.2.3

***Dr White:** there's a strong medicalisation of emotions that's going on, so we've got a cohort of young people who are coming through with a diagnosis of ADHD or some kind of pervasive development disorder that I'm not quite sure whether those dis regulation of emotions are purely fixed by tablets and I think there's quite a push for society to see um, emotions as abnormal and there for needing treatment and I think that's certainly increased in the last couple of years where I see people who are under distress and find it very difficult to deal with emotions that um, that are probably um a combination of social changes and um, kind of breakdown of society's normal coping strategies so that's my sense.*

6.5. Psychiatrists – Commonalities and Differences

Number of coded references for themes is shown in appendix V. However, given that there were fewer number of participants for this stakeholder group (i.e. 7 as compared to 15 service user interviews), an investigation of the number of coded references alone is of less value. Instead, it is useful to explore where consensus exists (or does not exist) across the psychiatrist interviews. This is particularly revealing, given that the all psychiatrists from the CMHT pathway, apart from one, were interviewed.

6.5.1. Common themes from psychiatrist interviews

The overall impression from this data is that a large part of the interviews with psychiatrists refer to themes at the interaction level. Presenting information, offering choice, the process of making decisions, and barriers and facilitators to an interaction, formed a significant part of these interviews. Themes that emerged at the relationship and system levels of analysis were less apparent. This trend in the data may be linked to how modern mental health teams are structured. In particular, the conceptualisation of the psychiatrist's role as an expert of psychiatric medication and consultative in focus may explain this trend. This is discussed further in section 6.4.2.

Looking at the themes by number of coding references in appendix V, the theme entitled 'Choice' is, by far the largest. Under this umbrella theme, the largest single sub theme refers to the importance of presenting information on a range of options, and exploring the pros and cons of these different options. This links to the themes presented in sections 6.2.1 and 6.2.2, and the service user having ownership and power to decide whether or not to take a prescribed medication. Indeed the value placed upon service users having ownership over the decision and the psychiatrist presenting information to enable choice, was apparent through the general question section of the interviews. However, while

valuing the importance of presenting information to service users, psychiatrists did acknowledge, that at times, choice may be either be limited or presented as a plan 'B', and at times arguments were constructed so as to avoid conflict in the encounter.

As alluded to above, however, this does not necessarily indicate that consensus was present, across the psychiatrist interviews. Looking for consensus in the data, one overarching theme was coded for all seven psychiatrists. This refers to the barrier of service users being ill as hindering involvement. Within this group, a majority (but not all) refer to 'lacking insight' as problematic for open dialogue. This is discussed further in section 6.2.4.

6.5.2. Areas of difference across interviews

As mentioned above, providing information was valued strongly by psychiatrists and seen as a crucial aspect of involving people in decisions about psychiatric medication, enabling greater control and allowing more informed decisions to be made. In particular, providing information on the side effects of psychiatric medication was seen as very important. There were, however, contradictory aspects to the theme of valuing full provision of information. Many psychiatrists acknowledge that the amount and type of information about psychiatric medication changes according to the situation. In addition, a sub group of participants confess that, at times and during certain encounters, information about psychiatric medication is withheld. This was, in the most part related to circumstances where the service user is deemed by the psychiatrist as lacking insight into their illness. In addition, a minority of participants discussed challenges of openly discussing sensitive or potentially embarrassing side effects, such as sexual dysfunction. However, there was not consensus across interviews in this view. Instead, other participants, when asked, strongly disagreed that information would be held back under any circumstances. See section 6.2.2 and 6.2.4 for further discussion.

Another aspect of difference relates to the critical incident component of the interviews. That is, in the recollections of positive meetings, a spectrum of response in service user involvement is observed in the data. For some psychiatrists, recollections of positive meetings were related to an example when the service user took the lead in the decision making process, and the psychiatrist presented balanced information, without unduly influencing the outcome. This is shown in the quote by Dr. Kos below. Other psychiatrists refer to a positive meeting that is more representative of ideals of a shared dialogue. For

example, the quote by Dr. White emphasises building a joint understanding and reaching consensus over the final decision, in a working partnership with the service user. However, other psychiatrists discussed positive meetings that were more reminiscent of a paternalistic style, where guidance is given and service users are more passive in the process. This is illustrated in Dr Blogg's quote, below.

***Dr Kos:** I think that I hope that I was able to **present two medications in a balanced way**, that really , although I felt quite strongly about uh the lithium, I really felt that I presented it in a balanced way that both has pros and cons and I think um in terms of thinking about her wellbeing I was pleased, I was quite pleased she took, it was not my advice because **I didn't advise her to take either of them, but she really made the choice** that I would have made as well..*

***Dr White:** I think what's positive is that you know we came into **a joint understanding**, that we agreed to disagree on some points but that we did manage to **get to a point that maybe well we could work on this** and I felt that in future if things would deteriorate then maybe **she would hear my voice** and my advice so I think that was positive that she didn't feel in anyway. And you know often people come here and say, oh you're not going to tell me to take or reduce my drugs or take this and I find that a very interesting view because I wonder where that comes from , this idea that I am going to tell them what to do*

***Dr Bloggs:** I think what stood outis that **he was the sort of person that would believe you**. His insight was limited, but he was the sort of person who would say **if you think this will help me then I will take it**, yes and he is also the type that has been ill for some time and .. he hadn't received a lot of help*

As such, contradictions in the data have emerged. On the one hand, the theme of valuing increased service user ownership, choice and control over decisions is present in these findings (see section 6.2.1). On the other hand, during the critical incident section of the interview, a more diverse spectrum of service user involvement is presented. This is suggestive of a gap between more abstract ideals and principles (in the main section of the interview) and actual practice (the critical incident component of the interview), perhaps indicative of hidden and insidious barriers present to achieving SDM in practice.

Finally, there were some differences in perspectives surrounding the role of the psychiatrist, and value placed on diagnosis and medicalised approaches in medication management practice. All psychiatrists viewed medication expertise as an important and defining aspect of their role. Moreover, whereas the majority of psychiatrists viewed medication as one tool in a wider bio psycho social approach, some psychiatrists placed

increased value on diagnosis as an important consideration for the final decision, guiding choice and also linked to the academic evidence base for medications. Others however raised concerns that there is an overly dominating role of diagnosis for medication related decisions, thereby distancing experiential knowledge and the service user perspective, and hindering collaborative dialogue. See section 6.4.2 for further discussion.

6.6. Chapter Summary

Thematic findings from interviews with psychiatrists have been presented at three levels of analysis: the interaction, the relationship and the system. At the interaction level the themes; presenting information; service user expectations; descriptions of being ill as a barrier and; valuing service user ownership are discussed. At the relationship level the theme of achieving an open dialogue is presented. At the system level, themes comprise; the mental health act and fear of coercion; and mental health service structures. There was less consensus in themes for the psychiatrist interviews and some contradictory aspects of the data emerged. These centre around: perceived ideal levels of involvement service users have in medication encounters, the value placed on service user perspectives and expertise, and how to maintain choice and present full information about the pros and cons of psychiatric medication, during more difficult times, or when a person is deemed to lack insight into their illness.

Chapter Seven. Thematic findings from interviews with CPNs.

Chapter Outline.

This chapter presents thematic findings from research interviews undertaken with CPNs, in phase one of the data collection. Findings are presented at three levels analysis: the interaction, the relationship and the system. A summary of the commonalities and areas of difference in the interviews with CPNs follow this. The chapter concludes with an exploration of the similarities and differences observed between the themes for the three stakeholder groups: service users, psychiatrists and CPNs.

7.1. CPN interviews - Background information

Eight interviews were conducted with CPNs, out of a possible total of nine within the CMHT pathway. One CPN did not respond to an invitation to participate. Interviews lasted between 45 minutes and 1 hour. Seven were female. All were experienced members of this community team.

CPN number	Pseudonym	Job title and Length of time working in ITT (at time of interview). Other background information	Gender
CPN 1	Hazel	Worked in pathway for approximately two years. Extensive previous experience of psychiatric nursing.	F
CPN 2	Heather	Worked in pathway for over two years. Extensive previous experience of community psychiatric nursing	F
CPN 3	Allison	Team leader and community psychiatric nurse. Worked in pathway for over two years and extensive previous experience of psychiatric nursing	F
CPN 4	Barbara	Worked in pathway for over two years. Extensive previous experience of community psychiatric nursing	F
CPN5	Mark	Worked in pathway for over two years. Extensive previous experience of community psychiatric nursing	M
CPN 6	Emma	Worked in pathway for approximately two years. Extensive previous experience of community psychiatric nursing.	F
CPN 7	Elsa	Worked in pathway for over two years. Extensive previous experience of community psychiatric nursing	F
CPN 8	Anna	Worked in pathway for over two years. Extensive previous experience of community psychiatric nursing	F

Table 7. CPN participant information

7.2. CPNs – themes at the interaction level

7.2.1 Service user gaining control

Alongside service users and psychiatrists, most CPNs also referred to the importance of the service user taking increased control and ownership over the decision making process (see Hazel, below). The sub theme of using medication as a tool, learning how medication is helpful and gaining self management skills emerged from interviews with CPNs (see Barbara, below). This linked with how many CPNs viewed their own role in medication management. Mark, in the quote below refers to his role as providing skills to encourage the service user to take greater control.

HAZEL... *I think it's always positive when a patient can come along and sit there and say, look, this is what I think would work for me, this is what I would like, and to be able to talk about it, and both of us to be able to talk about it, and both sit there and think, yes, this is an excellent idea and let's look at that and let's take it away, and I think, you know, it was all done in a very... yeah, in such a way that was... I mean she negotiated it very well.*
... And she was absolutely right with what she wanted. It was a really good plan.

BARBARA: *Because I think she gained an understanding about how medication could be useful and, how, you know, it had its place. But she was... but she was taking control appropriately for when she took it. I felt, yeah, she's got it now, and that left me feeling reassured about her coming off it this time.*

MARK: *What you really want, what I would really want is someone just to say, yeah, I get it, I, you know, I understand it, I recognise what I would be feeling would make me stop, I know what I'd be feeling that might make me want to increase it or to talk to someone about it and I recognise what a side effect would be, I know the best time of day to take it, I know that whatever, the various special indications or whatever, that they'd understand that.*
...So the job is about giving people skills really.
..Less than feeding them, because it's community rather than ward so it comes back to the idea of training and teaching I think.

7.2.2. Being ill as a barrier

All CPNs acknowledged that during periods of crisis, the level of involvement a service user has in the conversation, decreases. Similar to psychiatrists, 'lack of insight', or a service user not understanding they are ill, was mentioned as a particular barrier by the majority (but not all) CPNs. Heather, in the quote below, suggests that communication

may change during these more difficult periods, referring to the need, at times, to 'encourage concordance', but in the context of a trusting relationship (see relationship level, section 7.3). In Elsa's recollection of a positive meeting (the critical incident component of the interview) she reflects on the importance of knowing the service user and having established trust as being particularly helpful during these more difficult times. The importance of reinforcing information during difficult times is also mentioned by participants (see Mark, below).

HEATHER: *And particularly if someone's very ill and their insight is very poor, and you think, this person really does need to take medication, they're really unwell, it getting on the brink of maybe a delusions. Or somebody with depression, with psychosis, people losing touch with reality, it's important to find out, .. to support and listen and advise and yet encourage concordance. Without a trusting relationship there's no way because people will tell you they are taking it and they won't or they will tell you because they think that's what you want to hear. So, you know, when you have the patient in your hand, when actually, they know if they say, 'I'm not taking [the medication], it's disgusting it's crap', then actually.. you'll listen again and be there but you still try and encourage, because people are unwell, so you have a responsibility. So that's encourage not force*

MARK: *Well, obviously their state of mind while they're ill, if they're completely bonkers it's going to be difficult and you want to feel that you're having a rational conversation, that people are understanding what it is you're talking about. ... They've got to be able to retain the information. ... But I do think... I don't want to give the impression that we go, right, they're not well, we're not going to tell them, I don't think it's a matter of that, I think it's often more a matter of just keep repeating the information.*

ELSA: *The conversation, you know, when someone's as ill as that you're not going to really... [pause].. I think she wasn't really caring, because she wasn't well enough, but on the other hand I think she could see that at one level that things were not right, but someone was trying to help.*

I: *..but what was it about that, that for you was a positive meeting,?*

ELSA: *I think because... I think there was something there about a therapeutic relationship when I started with... we had that sort of relationship, so she was going to trust me and I think that's what it was, and that's kind of a nice feeling... So she was terrified about all things... the hallucinations instead of what the... but she could sort of relate to that, yeah. ... Yes. I think that's the essential thing really, I think that the relationship is so important that you establish that, so when people are like ill they will sort of listen to what you're saying, realise that you are there to try and help them, not to force them into doing something they don't want.*

I: *Yeah, yeah. yeah, no, I think that's a great example!*

ELSA: *Well I had been seeing her a long time and we had, yes, so she knew me pretty well, yeah, that was good..... Longer than she should have been, but there we go.*

7.3. CPNs - themes at the relationship level

Themes at the relationship level and the importance of the helping and therapeutic relationship emerged most strongly within the CPN interviews. Themes are comprised of: walking the journey, building an honest and open dialogue, and valuing service user expertise.

7.3.1. Walking the journey

The theme of walking together with the service user in a journey towards recovery was mentioned by all CPNs. CPNs referred to the importance of a supportive, long term relationship with service users. Heather's quote below refers to an example of a positive meeting (the critical incident component of the interview). Here, a journey through time and formation of a partnership is emphasised. Supporting service users through difficult times and celebrating success was also mentioned (See Anna and Heather). In addition, the importance of genuinely caring about the service user was emphasised as an important aspect of collaborative care.

HEATHER : *So there's a kind of walking the journey together, and sometimes he's pulling back a bit and I'm pushing forward and we were at different paths pulling in different directions, but actually kind of, slowing down, going back to his level, even going up to, that kind of thing together, that kind of push pull kind of stuff, but probably the success is about two people building up a mutual respect and real affection for each other and thinking I really care about you and I want you to be happy and I want you to experience peace and have a good life and when you are not well, you end up banging your head against a brick wall and trying to cut your wrists, kill yourself in prison and I have to really work hard for that not to happen, because I don't want to see you ill. That's the kind of thing, I know that's a very didactic approach but it's a kind of push pull.*

ANNA: *Yeah, yeah, but it's kind of, you know, it's more... I think it's more about, it's actually, you know, we'll walk shoulder to shoulder down this path.*

7.3.2. Building trust and honesty

Similar to the interviews with both psychiatrists and service users, CPNs emphasised the importance of building trust. Honesty was seen as crucial to a partnership being forged, which in turn was essential to a shared dialogue about psychiatric medication.

BARBARA: ... you build up a strong therapeutic relationship with somebody so that you can work together and it is essential that you have trust and you have honesty in that relationship, with a constructive relationship.

7.3.3. Valuing service user knowledge

Most CPNs also emphasised the importance of valuing knowledge the service user brings to the conversation. As part of this, CPNs accepted that disagreement was possible. Anna, in the quote below, refers to expressing her opinion, but is happy when she 'gets it wrong'.

MARK: But as long as you're clear in your own mind that that's the decision you're making, I think that's the point... ..is that people come from a point of knowledge.

ANNA: I think the thing I've learnt probably most of all is that you can't dictate or prescribe to somebody, it has to be collaborative, and even if sometimes you think, that wasn't the wisest thing you've decided to do, you have to go along with, and I will be honest with people and say, 'it's perhaps not what I would do.....let's hold on and see how it goes.' **And learning to know that sometimes I'm wrong, you know, the service user will come back and say, 'no, that was fine actually'.**
.. 'Oh, OK, I got that wrong'...'You know, that's great, I'm really glad that I got it wrong'.

To note, psychiatrists and service users also emphasised the importance of honesty and, at times, disagreement was considered a success⁵¹. However, as illustrated in Mark's quote above, CPNs also refer to service users coming from a point of knowledge, suggestive of a shared dialogue and sharing of opinions. Acknowledging fallibility (see emboldened section in Anna's quote) is also suggestive of more priority placed on valuing service user preferences and expertise, with genuine respect for differences in opinion. This was less explicit in the psychiatrist interviews.

CPN as the go between?

Within this theme, most CPNs referred to an important aspect of their role as relaying information to the prescribing doctor. CPNs emphasised their role as acting as an advocate for the service user in meetings, as well as being the 'go between' with the service user and

⁵¹ This emerged as a theme for service users: S. 5.4.2. Psychiatrists discussed the importance of honest open dialogue, although less reference was made to disagreement See S. 6.3.1

psychiatrist. This was seen to enable service user preferences and experiences to be better represented in the decision making process.

***ELSA:** And I feed back to the prescriber about what the patient tells me and my view on whether it's helping or whether... maybe that something else similar needs to be tried...*

...Usually I feel I'm a bit of a go-between between the psychiatrist or the GP who's doing the prescribing.

7.4. CPNs – themes at the system level

There were two emergent themes from CPN interviews at the system level: value placed on psychiatric medication, and doctor - patient asymmetry.

7.4.1. Value placed on medication

Medication was valued by CPNs as an important therapeutic tool that formed a significant part of mental health service offerings. However, for most CPNs, psychiatric medication was seen as one tool, as part of an integrated approach to care. Here, the role of medication was seen to vary according to person, their values and experiences, and according to the severity of illness.

***HAZEL:** I think it's significant but it's not the be all and end all. I mean the people that have severe enduring mental illness, it just have a significant place, with people that have more sort of neurotic conditions, it's... it's played less of a part but it has to be a consideration and again it has it's place, because I think its importance is different. I do think it has a place but you have to use it as part of a sort of integrated approach to care, its... medication alone isn't enough.*

Many CPNs also suggested that there had been a significant shift towards a more holistic approach in nursing over recent years, with the CPNs role in medication management moving from one of monitoring compliance to medication regimes, towards increased social and psychological intervention work. This was seen as a positive change towards service user involvement in medication management (See Mark, below).

***MARK** ...and actually nursing is much... It used to be all about medication, it used to be, go and see this person, make sure they're taking the damn tablets and while you're at it if there's anything else go on and deal with it... Well, now, it's much more, well look, let's look at psychological, operational interventions and social interventions and help people make a sense of where they're at,*

Challenges to collaborative decision making were mentioned within this theme. These consist of a pressure to prescribe, concerns over side effects and a lack of review of medication decisions. To note there were differences between CPNs interviewed in these sub themes.

Pressure to prescribe

For a minority group of CPNs, there was an increased pressure on psychiatrists and GPs to prescribe medication. This related to a cultural over reliance on the biological model of mental illness. This theme also emerged in interviews with psychiatrists (S. 6.4.2).

BARBARA:... *I think society expects to be ever so happy now, so people go to the GP wanting rather than kind of managing that changing their mood themselves.*

ALLISON: *I mean I think it's easy to call medicine the villain, but it's just what we've got, and I think it's how we use it that's the problem.....because I think there's that all or nothing thing about psychiatric medication while, you know, sometimes it's just a useful tool.. So I don't think we manage it for... I think, you know, I don't think we have the honest conversations and I don't think we manage it very well in the long term.*

Concerns over side effects

This sub group of CPNs also expressed concerns about the lack of open discussion and challenge about the serious and enduring side effects of psychiatric medication within mental health services. For example, Allison (see below) worries that there is denial amongst practitioners about the reduced life expectancy of clients being prescribed anti psychotic medication. This was related to a lack of alternatives (to psychiatric medication) being available.

ALLISON: *I mean, you know, it's a very conflicting story is psychiatric medication, because sometimes I see it as a necessary evil..... [but] it worries me how much we use and what we do to the life expectancy of clientsand that we seem to be in denial about largely. But sometimes, for instance, if somebody is absolutely distressed we don't have a system that we work in that we can provide a safe place, you know, we have no alternatives. ..I don't believe in mental illness kills you.....I think it's more likely to be the toxicity of the substances that we're giving people.*

However consensus across interviews was not apparent. Instead, other CPNs emphasised the helpfulness of psychiatric medication. A sub group found the use of analogies to other medical conditions useful in conversations with service users, playing down the potential long term or serious effects. Use of these analogies constructs psychiatric medication decisions as similar to that of general medical illnesses and treatment, thereby reducing the perceived dilemma in choice to take the prescribed treatment, and therefore potentially reducing the amount of full discussion likely about the pros and cons of psychiatric medication use. For example, Anna, below, uses the analogy of a chest infection and antibiotics, when describing antidepressant use to service users.

***ANNA:** Just the same way as if you came to see me and you've got a chest infection, we'd look at all the ways you might have been able to work it out for yourself, you've obviously tried those and that's why you're here and so you need to take the prescribed medication in exactly the same way as you would if you'd got a chest infection. And normally with a chest infection a course of antibiotics shifts it and you're back to your old self, and I'm hoping that with a course of antidepressants will have the same result and we'll do the same thing, we'll review you regularly, see how you're getting on and then, you know, if necessary we can change it, just like you would with an antibiotic. So... and that sometimes helps people to kind of get it into their head that it's an illness just like any other illness and it needs treating.*

Lack of review for psychiatric medication decisions

A number of CPNs acknowledged a problem that decisions were often made during periods of trauma or crisis. However, there was concern that less emphasis is placed on reviewing the decision once the service user feels better (or is more able to be more fully involved). This was seen as a concerning aspect of medication management practice.

***ALLISON:** once somebody's starting to feel OK, how you think about moving it on...and I think there still is a reluctance, you know, if it ain't broke, don't fix it.*

7.4.2 Doctor patient asymmetry

A number of CPNs suggested that changes in the system over the last decade had resulted in a more collaborative style of prescribing (See Mark, below). However, a sub group of CPNs referred to a passivity by service users and a culture of 'doctor knows best' as still impeding shared dialogue in medication management practice (See Allison and Heather, below). For Heather, structural factors such as class and education level were important influencing factors in how involved service users were likely to be.

MARK: *No, I mean it does seem to me that there is... the people are much more engaged, I think, in these decisions, than they used to be....It was very much you'd go and see a consultant, you'd answer a lot of questions [pause] you could be told what would happen to you....There wasn't a great deal of debate. I mean now when you're sitting with the psychiatrist there will usually be some discussion about, well, we think this, you know, we think an antidepressant may be helpful, would you be prepared to consider it? These are the benefits we think it might give you, these are the types of antidepressant available, I mean...*

ALLISON: *...But I think there's a lot of passivity about doctor knows best.*

HEATHER: *you will be more likely to be successful in your advice about medication routines, than you are if you are somebody who perhaps has a more passive stance when it comes down to a medical model or a disease management model ...'I haven't got the right to say the doctor knows best', so I think that a lot of it is reciprocate, middle class people relate differently to middle class people, and they are listened to more they hear more, they can make more things happen and that can be adverse effects for the patient, or it can be very helpful for the patient depending on the individual.*

7.5. CPNs – Commonalities and Differences

7.5.1. Commonalities across interviews

Themes relating to the relationship level of analysis are apparent in this data. This is especially striking when compared against the psychiatrist data, where more emphasis is found at the interaction level of analysis. CPNs emphasise the long term nature of medication management practice, being a journey over time and an ongoing experiment. CPNs strongly value a longer term relationship with the service user, emphasising walking the journey together and supporting the service user to take more control over medication decisions, over time. These themes were referred to throughout the interviews, both when CPNs were specifically asked about what is important for involving service users, but also when describing positive examples of meetings (the critical incident component of the interview).

CPNs often referred to their own role as a 'mediator', or 'the go between' with the psychiatrist, at times acting in an advocate capacity for the service user. CPNs also emphasised the caring components of the role and spending time with service users. CPNs

often felt they had a good understanding of service user preferences and current problems to consider for decisions about psychiatric medication. As such, CPNs saw themselves as a conduit of information to the prescriber or more specifically, the psychiatrist. Interestingly, some participants referred to being a medical prescriber⁵². However, these qualifications were not being utilised in this community team.

Another aspect at the relationship level which emerged strongly in this data was the importance of honesty in the relationship with the service user. CPNs felt they had a duty to impart their opinion to service users about a preferable option, whilst not controlling the decision.

At the interaction level, the importance of choice was not mentioned by CPNs (unlike psychiatrists). Instead provision of information about side effects, whilst important, was seen as in need of improvement. There was acknowledgement by CPNs that, at times, only selective information is provided and, at other times, more persuasive forms of communication are employed. Reinforcing information during periods of crisis was emphasised by CPNs.

Severity of illness and lacking insight were seen as challenges to involving service users by the vast majority of CPNs. CPNs also often mentioned problems of involving a minority of service users who were overly passive in the process, not expressing an opinion or preference. This was linked to the concern that some service users externalised problems and associated medication with a quick fix. This was seen as problematic for CPNs.

7.5.2. Differences between interviews with CPNs

Views surrounding the role of, and value placed on, psychiatric medication as a treatment in mental health services, differed between interviewees. A minority of participants expressed concerns about the ethical implications of prescribing medication associated with severe and enduring side effects. However, other CPNs expressed the view that medication was a necessary treatment for serious mental health problems, placing importance on biological aspects of understanding mental illness by using analogies to other medical conditions in the construction.

⁵² Two participants had undertaken relevant training and were qualified to prescribe medication. However, this was not being utilised in their role within this CMHT.

7.6. Exploring similarities and differences between stakeholder groups

This section describes the similarities and differences in themes that have emerged across the three stakeholder groups: service users, psychiatrists and CPNs. Exploring some of the apparent similarities and differences allows for some of the more subtle aspects of the data to be explored (e.g. what is not discussed by certain stakeholder groups). Table 8 presents similarities and differences by levels of analysis; the interaction; the relationship; and the system.

	Service users	Psychiatrists	CPNs
Interaction	<p>Similarities</p> <ul style="list-style-type: none"> • Service user gaining control • Being ill as a challenge for involvement • Reinforcing information and checking understanding <p>Differences</p> <ul style="list-style-type: none"> • Valuing service user knowledge and expertise • Being ill and difficulties in processing information and distress 	<p>Similarities</p> <ul style="list-style-type: none"> • Service user gaining control • Being ill as a challenge for involvement • Reinforcing information and checking understanding <p>Differences</p> <ul style="list-style-type: none"> • Service user ownership of decision • Lack of insight as a barrier to involvement 	<p>Similarities</p> <ul style="list-style-type: none"> • Service user gaining control • Being ill as a challenge for involvement • Reinforcing information and checking understanding <p>Differences</p> <ul style="list-style-type: none"> • Valuing service user knowledge and expertise • Lack of insight as a barrier to involvement
Relationship	<p>Similarities</p> <ul style="list-style-type: none"> • Open dialogue <p>Differences</p> <ul style="list-style-type: none"> • Walking the journey together and continuity of care 	<p>Similarities</p> <ul style="list-style-type: none"> • Open dialogue <p>Differences</p> <ul style="list-style-type: none"> • The changing role of the psychiatrist 	<p>Similarities</p> <ul style="list-style-type: none"> • Open dialogue <p>Differences</p> <ul style="list-style-type: none"> • Walking the journey together and continuity of care
System	<p>Similarities</p> <ul style="list-style-type: none"> • Dominance of psychiatric medication in MH treatment programs • The Mental Health Act – a barrier <p>Differences</p> <ul style="list-style-type: none"> • Stigma as a barrier • Fear of coercion • Doctor patient asymmetry 	<p>Similarities</p> <ul style="list-style-type: none"> • Dominance of psychiatric medication in MH treatment programs • The Mental Health Act – a barrier <p>Differences</p> <ul style="list-style-type: none"> • Pressure to prescribe as a barrier • Fear of coercion 	<p>Similarities</p> <ul style="list-style-type: none"> • Dominance of psychiatric medication in MH treatment programs • The Mental Health Act – a barrier <p>Differences</p> <ul style="list-style-type: none"> • Pressure to prescribe as a barrier • Doctor patient asymmetry

Table 8. Similarities and differences between stakeholder groups

From table 8, it can be seen that at the interaction level, all stakeholder groups value the importance of the service user having ownership and increased control in the decision making process. All stakeholder groups strive towards the service user achieving greater self management skills and gaining control in decisions about psychiatric medication.

Service users and some CPNs also refer to the value of service user expertise and knowledge in the decision making process. Overall, psychiatrists referred less to service user expertise and knowledge and less emphasis is placed on ideals of a meeting of experts⁵³. Instead, the vast majority of psychiatrists refer to the importance of providing choice and respecting the service user as having ownership over the final decision. Honest dialogue was also strongly valued (see relationship level below). The differences observed between the CPNs and psychiatrists often linked to practitioners conceptualisations of their own roles. Psychiatrists saw themselves as the medication expert and an advisor, providing detailed advice and choice and less focus was placed on continuity of care or establishing a longer term partnership. CPNs on the other hand referred to acting the conduit of information, helping to ensure service user preferences and problems are communicated in the decision making process, as a result of knowing the service user in a longer term and trusting relationship with the service user (see below).

On the other hand, less emphasis on service user expertise by psychiatrists, may also point towards a continued dominance of paternalistic practice. However, valuing a paternalistic approach was not prevalent in interviews with psychiatrists. Instead, a diversity in practice was found, from an informed model at one end through to a paternalistic approach on the other. This diversity was mostly apparent in the critical incident component of the interviews, perhaps suggestive of a gap between ethical ideals (emergent in the general questioning component of the interviews) and actual practice. Nevertheless, taken as a whole, fewer psychiatrists placed emphasis on the ideals of shared decision making, on reaching consensus, sharing an opinion and placing value on experiential knowledge. Finally, these differences between practitioner groups in the value placed on experiential knowledge may also be suggestive of a dominance of the medical model of understanding for psychiatrists, where medical expertise is more and experiential knowledge less at the fore.

⁵³ this theme emerged for some psychiatrists in the critical incident component of the interview

All stakeholder groups refer to the challenges surround being ill or in crisis for service user involvement in medication related decisions. Both practitioners and service users appreciate that often decisions about medication are made during periods of crisis, or distress. Reinforcing information and checking understanding was valued by all as important during these periods. Service users also value increased guidance during these periods.

Lack of insight, or the service user not understanding they are ill, was mentioned by both CPNs and psychiatrists, as a key challenge to shared decision making and was associated with a change in how information is presented and how medication conversations are constructed. Lacking insight was mentioned less by service users, who instead emphasised the problems of poor concentration, memory problems and anxiety and distress as being the biggest challenge to being involved during periods of crisis.

At the relationship level, all stakeholder groups emphasise the importance of achieving a constructive therapeutic relationship for meaningful dialogue. The importance of achieving an open and honest dialogue was especially emphasised by all groups.

Psychiatrists were, overall, less likely to emphasise the more supportive or caring aspects of the therapeutic relationship. In addition, less emphasis was placed on the longer term relationship. On the other hand, CPNs and service users referred to the importance of walking the journey together, establishing a long term partnership, being supported and feeling that the practitioner knows the person well. Service users, in particular, valued increased guidance during periods of crisis, in the context of a longer term trusting relationship. To explain these differences in conceptualisations, it may be important to consider the function and changing roles in mental health teams. Indeed, psychiatrists did highlight the changing role of the psychiatrist towards that of an expert advisor and performing more of a consultative role in the medication management process.

At the cultural and system level, concerns surrounding the increasing medicalisation of mental health problems emerged as a barrier to collaborative decision making across all three stakeholder groups. Within the theme, there were differences in conceptualisations across participant groups. Service users referred to feeling labelled, pre judged and feeling stigmatised hindering collaborative dialogue. For some service users, this was associated with receiving a diagnosis and a dominance of the medical approach in psychiatry. Some psychiatrists and CPNs on the other hand, refer to the trend towards an

increased medicalisation of emotions as an emergent problem for a holistic and collaborative discussion. Here practitioners felt an increasing pressure to prescribe, from service users and society more generally.

Service users and CPNs refer to doctor patient asymmetry as a barrier to service user involvement in decision making. Feeling like a child and being spoken down to is mentioned by service users, and CPNs refer to culture of doctor knows best as still being prevalent. This is less directly referred to by psychiatrists, at least at the system level of analysis. Service user passivity and 'wanting to be led', emerges instead from this participant group as a barrier, but this is more attributed as a service user preference, rather than a cultural phenomenon.

The context of mental health services, operating within a legal framework and specifically the role of the Mental Health Act in removing choice and freedom in the decision making process was acknowledged as a barrier to collaborative decision making across stakeholder groups⁵⁴. However, this was seen as less directly applicable in the context of this particular CMHT care pathway. The resultant fear of coercion emerged as a barrier to shared decision making across both service user and psychiatrist participants. Fear of coercion was not mentioned by CPNs, again, perhaps suggestive of the differing role the CPN performs to that of the psychiatrist.

7.7. Chapter summary

This chapter presents emergent themes from interviews with CPNs. Themes are presented at the system, relationship and interaction level of analysis. Commonalities and differences in interviews are explored. A particular emphasis is placed by CPNs on themes at the relationship level. Walking the journey together and achieving a trusting and open dialogue was strongly valued by CPNs. There were differences in how CPNs viewed the role of medication and its value in mental health services. The chapter concludes with a brief presentation of some emergent similarities and differences for conceptualisations of shared decision making between all three key stakeholder groups; service users; psychiatrists and; CPNs. These are described in detail above and are subsequently referred to in the discussion chapter.

⁵⁴ To note, this is not presented as a theme within the CPN interviews as it was only directly mentioned by one participant in the interviews.

These emergent findings are combined with the key observations and findings from the applied conversation analysis for phase two recorded meetings (see Chapter Eight), allowing for a rich conceptualisation of shared decision making to emerge.

Chapter Eight. Findings from phase two: an applied conversation analysis

Chapter Outline

This chapter supplements the thematic analysis of research interviews in chapters five, six and seven. Four meetings, where psychiatric medication was discussed between one psychiatrist and four service users, were recorded (phase two). The aim of collecting this data was to gain further insight into how decisions about psychiatric medication are reached in practice. The analysis of this data allows for a greater appreciation of the complexity of the medication management encounter and assists with building a rich picture of collaborative decision making in psychiatric medication management.

An applied conversation analysis (CA) has been adopted, focusing particularly on the power claiming and power sharing strategies employed by both participants in the meeting. The aim of this approach is to build an understanding of how decision making is shared in the encounters. This analysis uses a case study approach, incorporating relevant contextual information and the content of what is discussed in the meeting. The final section of this chapter explores how the applied CA findings link with thematic findings from previous chapters.

8.1. The recorded meetings - An overview

Four outpatient consultation meetings were recorded using a digital recorder (operated by the psychiatrist). The meetings all took place within the CMHT, between the same psychiatrist (Dr Kos) and different service users (Rosie, Carl, Linda, Lara), over a 6 month period.

All service user participants from phase one research interviews were invited to participate in this phase of the data collection. The initial aim was to record 10 such meetings, in different settings, with different practitioners (CPNs, Psychiatrists). However, the uptake for this phase of the data collection was poor⁵⁵.

Participants were approached individually about participation and written consent was obtained directly prior to the pre organised meeting. The meetings took the form of a psychiatric consultation / review meeting, at an outpatient centre in central Cambridge. All meetings could be described as a general progress or update meeting, with all service

⁵⁵ For further discussion on the possible reasons for recruitment challenges please see the methodology chapter.

users having previously met with Dr Kos⁵⁶. Researchers were not present in the meeting. Meetings lasted between 13 and 38 minutes.

8.2. Analytical approach

An applied conversation analysis was undertaken, assisting in understanding why a conversation happens as it does and emphasising the dynamics of the encounter. This analytical approach allows for the context of the meeting to be examined and (of particular importance to psychiatric medication management) for an exploration of what is and what is not discussed in the meeting. For further rationale and discussion please see the methodology chapter, section 4.4.1. A case study presentation style has been adopted, allowing for the inclusion of relevant interview data from phase one, with the aim building a rich picture of medication management practice. In summary, both the 'how' (the dynamic of the conversation) alongside the 'what' (contextual information and content of the meeting), is presented in this analysis, through the use of a case study format.

Within CA in general, it is important to clarify which type or 'genre' of meetings are being explored, as this influences which discourse cues are deemed as usual or unusual in this context. The medication management meetings recorded fall within the genre of an 'institutionalised' dialogue between medical practitioner (the psychiatrist) and mental health service user (Heritage and Clayman, 2010). There has been a significant amount of previous research which has explored the doctor patient institutional interaction, although less CA research has occurred in the psychiatric context (Mikesell, 2013; Drew et al, 2001). The central tenet of this body of research, is that an institutional interaction is systematically asymmetrical, in contrast to what is seen as the ideally equal nature of every day (non institutionalised) conversation (Hutchby and Wooffitt, 1999). Here, standard activities are suffused with the exercise of authority, from patients first having to justify the medical visit to a more knowledgeable clinician, through to diagnosis, where the human experience of symptoms and suffering becomes a medically 'validated' disease and treatment is proposed (Heritage and Clayman, 2010; Heritage, 2013). It is suggested that this authority has two main sources, - the dependency of patients who are unable to solve their problems and the cultural authority of science (Starr 1982).

⁵⁶ For Linda, this was only the second meeting with Dr. Kos, whereas all other participants had a longer established relationship.

Regardless, the literature shows that there is a direct relationship between status and role, on the one hand, and discursive rights and obligations on the other. In the process of the psychiatric encounter, status is reinforced by claiming 'speaker rights' such as the right to finish a point, take a turn, or to pursue a topic. For instance, there is extensive research which shows that doctors typically ask far more questions than patients and those questions tend to be much more topic directing than the few that patients do ask (McCoul and Hapley 2001; Hutchby and Woofitt, 1999; Drew and Heritage, 1992). In psychiatric consultation encounters, psychiatrists are likely to construct and control topics in a conversation and often choose not to maintain certain topics proposed by service users (Quirk, 2007, McCabe 2002). The analytical approach in this chapter draws on this research. However, as opposed to exploring the overt asymmetry, through the examination of doctors' discourse cues and strategies alone, I have also incorporated an examination of the active and power claiming strategies that service users employ (Cordella, 2004; Ainsworth Vaughn, 1998). This emphasis on a two way interactional process was deemed to be relevant for this analysis, where an exploration of shared dialogue is necessary. Ainsworth Vaughn's research, conducted in chronic medical care contexts (1998) focuses on both the active power claiming strategies service user's employ as well as exploring the power enabling approaches clinicians adopt. Her research suggests that, at times, the doctor patient encounter moves towards the genre of a 'conversation', with terms such as co-constructed knowledge becoming more applicable to the discourse encounter between doctor and patient. Other CA studies have focussed exploring the *voice of the lifeworld* in medical encounters, where patients present relevant medical information in context to their own lives and goals. Here a greater value is placed on the service user's experiential knowledge and increased respect in the encounter (Barry et al, 2001; Mishler, 1984; Ainsworth Vaughn, 1998)

The analytical approach builds on this work and explores the power claiming activities and strategies employed by both participants; the psychiatrist and the service user. I explore how the four meetings compare to what is known about institutional talk (questioning, control and social status) and investigate whether more power sharing forms of communication are employed in these encounters(e.g. more conversational strategies). By making explicit the discourse cues the psychiatrists and service users use, the complexity of shared decision making for psychiatric medication management is explored. This complexity is supplemented by a presentation of the striking contextual features of the conversations and the incorporation of interview data from the

participants to assist interpretation of the existing enablers and challenges for collaboration in the decision making process.

The key power claiming and power enabling discourse strategies incorporated into this analysis are shown in table 9, below. References to relevant literature are provided. Included in this table are the power claiming strategies undertaken by the psychiatrist (e.g. McCoul and Clayman, 2001; Hutchby and Woofitt, 1999; Heritage and Clayman, 2010) and the strategies employed by the service user to assert power in medical encounters (e.g. Cordella, 2004; Ainsworth Vaughn, 1998). Finally this table includes discourse strategies proposed to be supportive of more co-constructive dialogues, associated with the 'conversational genre' (as oppose to an institutional interaction) (e.g. Mishler, 1984; Barry et al 2001; Ainsworth Vaughn, 1998).

Power claiming resources applied by doctors	Power claiming strategies by service users (Adapted from Ainsworth Vaughn, p.181)	Strategies to promote co constructive dialogue (Adapted from Ainsworth Vaughn, p. 175)
Interruptions that either disrupt the topic or claim the flow (James and Clarke, 1993). This would not for example, include, affirmatory gestures such as 'yeah, uh hum' which do not disrupt speaker rights and may indeed be supportive to topic maintenance.	Carrying out potentially face threatening acts through the use of resources, such as <i>ambiguous rhetorical questions with an ambiguous voice</i> , to either get cooperation or to question competence of the doctor. This is seen as a highly aggressive and unusual act in institutional dialogue such as this.	Repetition, furthering questions, inference to promote topic maintenance
Questions are an important aspect of how psychiatrists maintain power in the dialogue, controlling the topic and speaker turn in the conversation (West, 1984), and are used by psychiatrists a tool to deflect or disengage with a unwanted topic (McCabe et al, 2002).	Questions are an important aspect of how service users exert power by controlling topics and speaker turn. Also the use of <i>treatment questions</i> to propose treatment. These are suggested to be one of the major ways patients propose treatment whilst not threatening the psychiatrist's social identity	Rephrasing to promote reciprocal topic transitions
Invoking structural affiliations , or referring to position and structural forms of power in the encounter, create more of an asymmetrical encounter between the psychiatrist and the service user (Ainsworth- Vaughn, 1998).	Offering a <i>candidate diagnosis through the use of narrative</i> , allowing for a greater appreciation of experiential understanding in the decision making process and allowing a plausible alternative candidate diagnosis by the service user.	Formulations of shared cultural knowledge and story telling
	Co Construct diagnosis. As above, but building a shared understanding and consensus over the decision	
	Framing the medical encounter as 'friendly' invoking favourable cultural schemas of self.	

Table 9. Discourse strategies of importance to the chosen analytical approach

8.3. The meetings

Dr Kos

All meetings recorded took place with Dr Kos⁵⁷, a consultant psychiatrist in the CMHT. Dr Kos has experience of practising psychiatry in a number of different settings and has worked within the NHS for a number of years. Quotations from the research interview with Dr. Kos are presented in chapter six, pages, 134, 136 and 143. In particular, Dr Kos discusses the importance of service users having ownership and taking increased responsibility for managing mental health problems. Dr Kos sees her own role as presenting a balanced argument for the pros and cons of different psychiatric medication alternatives (see page 143). She was the only psychiatrist interviewed who disagreed that lacking insight would not prevent a person being involved in decisions about psychiatric medication.

Transcription process

Only sections of the recordings where psychiatric medication is discussed have been fully transcribed, with researcher notes included for the remainder of the meeting content. The Jeffersonian approach to transcription was employed to retain the characteristics of speech delivery, such as, pauses, overlap, stress, intonation and pace (See Atkinson and Heritage, 1999). Transcription symbols and conventions are described in appendix VIII. An example of a full transcript from this phase of data collection is provided in appendix IX (Rosie).

8.3.1 Case 1: Rosie

Rosie (female, 24) has been in contact with Dr Kos for a number of months, but has recently missed a few scheduled routine appointments. Rosie has previously had contact with an occupational therapist, but does not currently have a CPN or contact with other practitioners from the team. Rosie has recently been in contact with the out of hours crisis team. At the time of the meeting, Rosie was being prescribed an anti depressant, *Venlafaxine* and the anti psychotic medication, *Aripiprazole*. Rosie has been prescribed various psychiatric medications for approximately 8 years. Quotations from the research interview (phase one) are shown on pages 111, 113, 117. In particular, Rosie mentions that she doesn't feel very informed about psychiatric medication and she would value

⁵⁷ all names are pseudonyms

more time to talk about the pros and cons of taking psychiatric medication. Rosie refers to conversations not being 'on her wavelength' with a lack of shared understanding of her problems. Specifically she mentions that she would like more discussion about hearing voices and her experience of this. Rosie also suggests that, at times, she is not very assertive in conversations, preferring the psychiatrist to take the lead. Rosie, when asked, responds that the psychiatrist is the person to make decisions about her psychiatric medication.

This meeting lasts 22 minutes, of which 8 minutes have been transcribed⁵⁸ as the conversation concerns psychiatric medication. At first glance this meeting looks like a typical psychiatric encounter. It is asymmetrical in power, with Dr Kos asking questions and Rosie providing short answers around medication, being rather passive in the conversation. However at the point later in the conversation when the decision is made about medication, Rosie does take a more active stance, using many power claiming activities. In addition, the psychiatrist cooperates with Rosie's claims to power. This suggests the encounter moves, at this point, towards a shared dialogue.

The key decision concerning psychiatric medication in this meeting is to change the type of anti-psychotic medication. This is shown in the following except, at approximately 12 minutes into the conversation. Medication had been talked about previously, at two prior points in the encounter (at 6.00 mins and 9.40 mins).

Time: 11.58 P=Dr Kos; R=Rosie (+same for cases 2-4)

38. P: But at the moment you don't fee:l that uh they are excluding you or or they seem to be or

39. R: =I don::t kno::w I find it so::o difficult to get past my own moo::d [

40. P: [yes yes

41. R: and the voices as well

42. P: [hum um

43. R: which leads me to my next que::stion (.) would it be::e possible to try a different

44. medication at sometime?

45. P: Yes I think it might be a good idea to see whether you have any (.) uh (.) I mean we switched

46. to aripipazole simply because of the side effects you had on on a amisulpride and uum (.)

47. and it might be worth to to try something different because even the combination of the

48. two when you were taking a very low dose of amisulpride then it seemed to work (2)

49. because of the side effects

50. R: = because of the [side effects]

51. P: [side effects exactly (.) so u::m (.) in terms of other medication I mean are

52. you happy on Venlafaxine in terms of the mood do you think thats that working

⁵⁸ Rosie's full transcript is provided in appendix 8, as an example transcript. A summary of the content for remainder part of the meeting is detailed in this transcript.

53. R: Yes=
 54. P: YES yes we we will not change that so really the question is whether we should change he
 55. aripriprozole uh the afilofy to something different (.) in terms of uh (.) a group of medication
 56. which are the same group of medication you you you've taken amisulpride and it has side
 57. effects and the other ones are olanzapine uh quetiapine resperidone have you had any
 58. experience with any any of these =
 59. R: Unfortat::ely [
60 P: ^ALL OF them=
 61. R: Most of them [
 62. P: Most of them
 63. R: =no::ot [olanzapine] but all the rest Ive tried risperidone I find quite str[ange]
 62. P: [uh hum] [huum]
 63. R: quetiapine I got (.) I felt quite [fra::ile] with it and um (2) what was the other one?=
 64. P: [hummm]
 65. P: Uh (1.) uh olanzapine I think olanzapine what you mentioned
 66. R: Olanzapine I haven't tried
 67. P: Yes yes[
 68. R: [Ive heard that makes you eat lo::Ads so
 69. P: Yess I mean this this can this can be a side [effect] yes
 70. R: [hummm] OKay (.) mayb::e a low dose would be Okay=
 72. P: Yes yes yes and in terms of the uh the problem you had with the amisulpride I think it's less
 73. likely with olan::zapine (.) so your prolactin level was quite high even on the small dose of
 74. amisulpride I hope that much less likely on olanzapine BUT I think what we should do we
 75. should have a prolactin level tested now just to have a baseline level and probabl::y ab::out
 76. a couple of weeks later just to see whether you have any problems on olanzapine and well
 77. keep an eye on your uh on uh your eating and on your weight as well. SO IF you if you would
 78. join the gym no::w that would be a very good idea because then then uh (.) then you might
 79. be able to to kind of control the the weight gain, the weight gain unfortunately can be side
 80. effects with the olanzapi::ne=
 81. R: Would the la::dy in the social inclusi::on (.) help me with that?
 82. P: Yes I think I think what we should do just uh (.) because um Charlie is no longer Charlie is on
 83. sick leave and you don't really need THAT kind of support that you have been receiving from
 84. Her

Time: 15.10.

In this excerpt, the initial topic change is initiated by Rosie (see lines 38-45). This is in response to a question asked by Dr Kos, in such a way that a new topic is introduced. Previous to this excerpt, the conversation for a few minutes focuses on Rosie's concerns about peer pressure from her housemates to drink alcohol. The question in continuation of this topic (line 38) leads Rosie to raise a new topic (hearing voices) which Dr Kos maintains by affirmative overlapping talk (yes, hum um) thereby allowing Rosie to continue the new topic.

This topic change strategy to claim her speaker rights is directly followed up by Rosie by proposing a treatment using a *treatment question* in line 43 and 44 (emboldened) by asking if she can change her antipsychotic medication. Here, Rosie is able to ask for a

review of her anti-psychotic medication, without directly stating that she is unhappy with a previous decisions concerning this medication (and thereby threatening the psychiatrist's social identity).

Dr Kos immediately supports and agrees to the treatment question (lines 43 and 44), whilst, at the same time, returning the form of conversation to that more in line with a traditional doctor patient encounter, through the presentation of treatment proposals/options and by asking questions. Saving face and preserving social identity is maintained at this point by Dr Kos (lines 46 – 47) by restating the previous rationale the current medication, before returning to Rosie's question and presenting new medication options. At one point in the subsequent conversation Dr Kos seems a little taken by surprise (line 60). Her voice is raised and higher than normal (unusual for this person in dialogue). This follows the presentation of possible treatment choices and Rosie's response that she has unfortunately already tried the proposed medications. The expression at this point in the conversation serves to prompt Rosie to explain further her experience with previous medications and Rosie proceeds with the narrative of different medications she has tried and their side effects. The final decision to try a low dose of Olanzapine is proposed by Rosie (line 70).

From a discourse perspective, this dialogue is relatively shared, with Rosie using some power claiming discourse strategies to reclaim her speaker rights. Dr Kos seems very happy to allow Rosie to take more control in the meeting, whilst at times preserving social identity rights and saving face in the encounter.

However, it is worth considering the broader topic of conversation in this meeting in order to understand how 'shared' the decision making process is. Whilst Rosie does assert herself at times during the conversation, it is relevant to note that little attempt is made to explore Rosie's concerns about side effects which Rosie raises in line 68 - 'I've heard this makes you eat loads'. Dr Kos responds and states this is a side effect, without further exploring how important a consideration this may be for the decision. Instead the conversation proceeds with Rosie directly stating 'a low dose may be OK' (lines 70) and the conversation then quickly moves to discussion of management strategies for the possible weight gain (lines 73 - 80). One of the fundamental aspects of SDM as described by SDM theorists (see literature review chapter) is the priority placed on jointly weighing up the pros and cons of any option. In the above excerpt, considerations of serious and

common side effects associated with an anti-psychotic medication are not fully explored and this absence of discussion is apparent.

This lack of further discussion about potential weight gain as side effect of the proposed medication is further evident, when examining it in the context of the excerpt below, which occurs at the onset of the meeting.

7. P: [yeah HOW do you find uh the aripiprazole do you have any problems at all and the side
8. effects with the [
9. R: [UUM I get quite sle::py [
10. P: [uh hum
11. R: =um in the mornings its very difficult to g::et u::p[.
12. P: [uh hum
13. R: =E:ven if I go to bed at t::en I could still (.)[wake up] at te:n or twelve e:ven (.) u::m (2) nnn
14. P: [uh hum]
15. R: apart from that its OKay.=
16. P: Its OK. So (.) Umm so there was also concern about we::ight gain when you went on the
17. amosulpride DO you find that you uh might have lost some weight since you are on the
18. aripiprazole
19. R: Yeah=
20. P: yes:s 9.) so it defina << ley but the voi::ces are slightly [bit worse]
21. R: [uh hum]
22. P: Do you think it is because of the medication ofor? because you had a job at that ti::me and
23. were more busy busier [
24. R [UUHH actually I have to admi::t that I have been dri::nking alcoho::ll aswell
25. s::oo 23. u::mm that's pro::oba::bly the thing to consider =

In the above excerpt in lines 16-18, Dr Kos refers to a previous medication (Amosulpride) and Rosie's previous problems of gaining weight as a side effect from this medication. Dr Kos states that the change to her current medication (Aripiprazole) was related to this adverse effect. As such, the absence of discussion about weight gain later in the conversation (see previous excerpt) is concerning, given Rosie's previous problems with this side effect.

In summary, the dynamic of the conversation about medication appears relatively shared, given its institutional nature, with Rosie asserting speaker rights at different points, and at times, directing the topic and exerting her preferences towards making a change in her anti-psychotic medication, due to continued problems related to hearing voices. However, there is less evidence of a full discussion about the pros and cons of making a change and in particular the adverse side effects of weight gain are not fully discussed or considered in the decision. In addition, the list of options Dr Kos presents (i.e. other medication in the same class of second generation anti-psychotics), may be somewhat limited. For example,

there is no exploration of both, other medication types, or other, non medication alternatives for the problem that Rosie presents (hearing voices). As such, whilst the dynamic of the meeting was partly shared, and Rosie is able to, at times, exert control and express her preferences, the full requirements of a shared decision making process are not conformed to.

8.3.2. Case 2: Carl

Carl, (24, male) has been in contact with Dr Kos for a number of months and also receives services from a CPN and occupational therapist. Many decisions concerning psychiatric medication have been made in collaboration with the psychiatrist and GP. At the time of the meeting, Carl was being prescribed an anti psychotic, *Quetiapine*, and an anti depressant, *Sertraline*. Quotations from Carl's research interview (phase one) are shown on pages 109, 116, 120. In particular Carl refers to valuing guidance from his GP and psychiatrist when making decisions about psychiatric medication and sees his own role as being open and honest, providing all relevant information, enabling the decision to be made by his psychiatrist/GP. He strongly values his ongoing positive relationship with his GP and appreciates feedback on his progress, in a longer term relationship with his prescribers. He mentions past disagreements between practitioners concerning psychiatric medication, yet sees this as positive, illustrative of an open honest dialogue.

This meeting was a review meeting to discuss Carl's general wellbeing and progress. The meeting lasts a total of 13 minutes, of which 3 minutes were spent discussing psychiatric medication. Most of the meeting was spent discussing Carl's progress in looking for new career opportunities and a recent voluntary position that he hopes to start in the near future. Carl reported feeling generally positive and talked about plans for the future. The psychiatrist often made positive comments such as 'very good' throughout the encounter and reference to how things have improved. No change to psychiatric medication was made at this meeting.

As the following excerpt shows, the encounter appears asymmetrical in power. Carl makes no real attempt to claim speaker rights or take power in the conversation. Congruent with the interview, he seems happy to conform to the traditional 'patient' role and provide information to the psychiatrist, as requested.

This excerpt forms part of the first of two instances in the meeting where medication is discussed. The second instance is very brief, with the psychiatrist reinforcing no change to medication routine.

Time: 6:00

32. P: yes yes (2) do you have any problems with any side effects with the medication [quetiapine]at all?
 33. C := U::MM
 34. P: [you take se::traline as well and
 35. C: [um, yeah no but I don't think there is any problem, any
 36. possible effects from the side effe u::h medication I think that at times I try (1) u::h (1) f fight
 37. against it but in the sense of I'm starting to feel tired and NO NO I'll just do five more minutes
 38. five more minutes
 39. P: = uh ye::ess
 40. C: and I think that sense of its happening but otherwise yeah I'm trying to get as much as uh
 41. think just to reme::mber to take my medication at certain times uh in the e::vening definitely (.)
 42. P= In the evening what time to do tend to take
 43. C = I t::ry and take it by half nine
 44. P = half nine oh right and when you wake up in the morning that's when you start feeling a little
 45. bit dro::wsy or or ?
 46. C: = um NO (.) in the morning I'm generally uh generally alright it takes me only ten fifteen
 47. minutes to feel aw::ake
 48. P = that's not too [bad]
 49. C: [UM u....hh its (2) generally maybe in the evenings after I've taken it that I feel the
 50. drowsiness coming on, but I do::n't take myself off to bed in the evenings us::ually
 51. P: [uh hum, hum] ,
 52. C// th::AT I think that's the attitude that I have possibly got to change about it really =

Time: 7.36

The asymmetry in power in this excerpt is illustrated by the use of questions in the encounter. Here Dr Kos uses multiple questions thereby controlling the topic and asserting turn taking power (lines 32, 42 and 45). Carl does not ask any questions in any of the excerpts transcribed.

However, throughout the meeting, Carl nevertheless changes the focus of the topic and the new topic is readily adopted by Dr Kos, through topic maintenance strategies. The excerpt below is a good demonstration of this:

Time: 5:00

1. P: = Um and no problems with your sleep eith::er?
 2. C: = um NO, no, not not not since uh ((.) (laugh) so I've found recently just after Christmas started
 3. taking the right amount of queti::apine [
 4. P: [Yes
 5. C: I only had seventy five milligram t:able::ts
 6. P: [yes

7. C: No 25 milligram tablets and I thought they were fifty's
 8. P = ^OH right
 9. C: [so
 10. P: [SO you were taking actually seventy [five]
 11. C: [ye::s, yeah but yeah]
 12. P: yeah, ye::s And since Christmas so it's about [two months] that you were taking
 13. C: [uh hum]
 14. P: = about[one hundred and fifty]
 15. C: [yeah ye:::ah] (yawns)
 16. P: = And uh you are sleeping better
 17. C: = U:::H I'm generally sleeping bett::er I::m more able I'm I'm more ABLE to wake up=

So here, in response to the question (line1) about sleep, Carl goes on to change the topic (dose of quetiapine). Dr Kos responds with affirmatory gestures (yes, yes) and topic maintenance strategies, such as rephrasing (lines 10) and anaphora (or rephrasing information using a question - lines 12, 14) to encourage Carl to continue this new topic. When this topic appears to be exhausted by Carl, (lines 15 and a yawn), the psychiatrist returns to the previous topic (sleeping, line 16).

As such, whilst the character of this meeting appears asymmetrical in power, when looked at in terms of use of questions to control the dynamic and topic, , there is, nevertheless, evidence that topics are being co constructed . Carl maintains some power over which topics are discussed and Dr Kos appears happy to maintain new avenues or topics that Carl proposes. It is possibly important to note, however, that no problem is identified in this meeting and subsequently, no decision about medication is required. Therefore the weighing up of pros and cons is not necessary and the potential amount of conflict is limited.

8.3.3. Case 3: Linda

This is only the second meeting between Linda and Dr. Kos. Prior to this, Linda has seen psychiatrists in other teams. Also, at the time of this meeting Linda was seeing two other psychiatrists in the eating disorder team and rehabilitation and recovery pathway teams. To note this is not usual in the context of this care pathway and may be indicative of either a period of crisis at the time of the meeting and/ or complexity of the problems.

Linda was being prescribed 450 mg *Venlafaxine*, an anti-depressant and *Gabapentin*, a mood stabiliser. Both prescriptions were issued by other psychiatrists, prior to this meeting. Linda has a number of years experience of psychiatric medication and has also

previously received Electro Convulsive Therapy (ECT), a rare and controversial therapy in this context, often used only as a last resort (NICE, 2010). Quotations from the research interview (phase one) are presented on pages 113, 120. In particular, Linda refers to valuing a shared discussion with prescribers about psychiatric medication, which is personalised to her situation and where different forms of knowledge (experiential and medical) are appreciated. She states, when asked that decisions are usually made in collaboration between herself and the psychiatrist and also values the ideals of building consensus in the final decision. Receiving comprehensive information about side effects, as well as the biological mechanisms through which medications work, was emphasised. Linda refers to a previous negative meeting where she experienced a breach of trust with her previous psychiatrist. Unlike the majority of other interviews, however, Linda does not talk about specific helpful relationships as being an important aspect of being involved in decisions about psychiatric medication, and in general, less themes are present at the relationship level of analysis.

The meeting in total lasts for 38 minutes, by far the longest of the recorded meetings. Medication related conversation lasts for approximately 8 minutes. There is no direct change to prescription as a result of the meeting. However, the time of day the medication is taken is changed in this meeting. Plans for future possible changes are also discussed, including the introduction of tryptophan, an amino acid supplement and the future consideration of the anti-psychotic, *Quetiapine* and/or a course of ECT.

This discourse is highly asymmetrical in speaker rights, with Dr Kos asking all of the questions throughout the dialogue. Dr Kos also makes direct treatment proposals on a few occasions, as illustrated in the following excerpt.

Time: 29.30

16. P: So at the moment you take (.) let's just see if it's in here yeah uh you are taking a Venlafaxine
 17. four hundred and fifty milligrams um and the dose has just been increased about ten days
 18. ago a week ago
 19. L: yea::h
 20. P: (.)= uh are you happy with the medication? Do you have any side effects at all or?
 21. L: I haven't noticed any (2)
 22. P: And you have been taking Venlafaxine in the past so it's actually the second time you are
 23. taking (.) [sigh] but in the past you were also taking it with a combination of different
 24. medication
 25. L: um ye::s I was on it was (.) um (4)
 26. P: mirtazapine

27. L: (.) yeah, and [um] L: and I think I was also on ?[premasasine]?[promazine]? at the same time
 28. P: [yeah]
 29. P: = [hum] AND um um
 30. L: [so]
 31. P: = and uh (2) if you you took different combination different medication uh (.) do you
 32. remember which of those you find the most beneficial at all?
 33. L: um (7) from what I rem::ember um they were all (3) seemed to (2) work for uh short while
 34. but then the effects just stopped and my mood went down again (3) so
 35.. P: [sigh] I mean (.) at the moment because you just increased the dose I think we have to wait a
 36. little while to see to assess how things are going. You are taking other medication as well,
 36. gabapentin, why gabapentin was prescribed for you?
 37. L: = Um, (.) I had really (2) bad (1) muscle pains
 38. P: Yes
 39. L: in my legs and I couldn't really do anything (1) so it <was for that
 40. P: And do you still take the gabapentin
 41. L: yeah
 42. P: yeah and what dose do you take?
 43. L: a hundred
 44. P: a hundred
 45. L: daily
 46. P: yeah a hundred daily. You have it once a day
 47. L: Um Once a day=

In this excerpt (lines 16 - 47), Dr Kos asks a total of nine questions, thereby having control over who speaks and control of the topic. In lines 34 and 35 Dr Kos also makes a statement that no change to medication can be made today, in order to give the previous change a chance to take effect. This is immediately followed by another question in line 36, thereby continuing the pattern of controlling and changing the topic. As mentioned above, this was only Dr Kos' second meeting with Linda, so the use of many questions may also indicate that formulation and assessment of Linda's mental health problems is a key aspect of this meeting.

On the face of it, Dr Kos is maintaining a highly asymmetrical form of dialogue and extensively using many power claiming strategies through the conversation. However, there are also many demonstrations in this short excerpt, of Dr Kos attempting to engage in a more conversational style and encourage more shared dialogue. For example, in lines 40 through to 47, Dr Kos repeats Linda's responses providing encouragement for additional narrative by Linda. Dr Kos, at no point interrupts Linda's speech. At other points, Dr Kos maintains a significant pause or allows a silence to continue, thereby encouraging Linda to take speaker rights and introduce more narrative into the dialogue. For example, in line 30, Linda has finished her previous sentence with 'so'. This was at a point of overlap in talk, but Dr Kos attempts to allow Linda to continue by pausing for two seconds (a significant pause in speech), yet no further interruptions are made by Linda.

Indeed and interestingly, at no other point in this excerpt does Linda's talk overlap with Dr Kos', which is rather unusual in spoken dialogue and in contrast, for example to the other recorded meetings presented in this chapter (e.g. see Carl, page excerpt 14, where Carl is seen to regularly interrupt during the dialogue). As such, this excerpt suggests a more strikingly passive stance being taken by Linda in this dialogue, with a sense emerging that Linda may have no preference to have increased say or power over process of the dialogue.

This pattern continues through the subsequent excerpt:

48. P: = Yes. Um (3) you mentioned that you are purging in the morn::ing and you are supposed to
 49. take the medication in the morning, so when you take the medication do you tend u::h (2)
 50. make yourself vomit after that^ or how long do you tend to purge yourself after medication?
 51. L: Um (2) why u::m (1) I take my medication after I've had breakfast so that's normally about
 52. eight O clock [um] and (.) then its normally sort of about mid morning that I would (.) binge
 53. and purge
 54. P: [Yes]
 55. P: = So about 10 O clock
 56. L: (1) yeah
 57. P: yeah So um so I think we might have to to look into that whether the medication actually
 58. absorbs (1) until then or (.) you are no::n responsive or partially responsive that that on
 59. some of the days you are not getting any medication sometimes I mean you mentioned that
 60. purging happens about three times a week four times you get the right dose but but three
 61. times you might not get the full dose and would you (.) would you be able to take the
 62. medication u::h after you purge yourself like at twelve O clock rather than then after
 63. breakfast.
 64. L: yeah
 64. P: = Can we try this way to see uh um to see uh whether you will get actually u::h a proper
 65. dose of medication (.) and uh (3) and uh I think we should leave probably a week, at least
 66. another week at this dose, but if you feel that the mood is still plateaued at all then I think to
 67. discuss with Dr Shara as well and probably adding something in addition [might] be a good
 68. idea
 69. L: [yes]

In this excerpt, Dr Kos makes a direct recommendation, which is agreed to by Linda (lines 60 - 65) about plans for to change the time of day for the medication. This follows on from a series of questions and short answers provided by Linda about her bingeing and purging behaviour. It is striking to note that the topic of the eating disorder behaviours are not further investigated by Dr Kos, and are instead seen as something to be worked around in the discussion of medication. It appears from this that Dr Kos does not see the eating disorder problems as part of her remit, and instead focuses on performing her role as the

medication expert⁵⁹. This may, in part, be explained by Linda's contact with another psychiatrist from the eating disorder's team, thereby restricting Dr Kos' broader remit to explore Linda's experiences of an eating disorder. Once again, however, Linda makes no attempt to either introduce more narrative into the dialogue, take control of topics, or assert her preferences in the conversation.

However, later in this dialogue, there is evidence that Linda does take more of an active stance. In the following excerpt, Dr Kos seeks Linda's opinion on future plans (lines 69 - 70) which she responds to by making a treatment proposal (future use of Quetiapine / ECT - lines 71-72), thereby claiming some speaker rights, but nonetheless, in a highly mitigated way. Here, Linda mitigates her preferences by distancing herself from the proposal, instead making use of a third person in the dialogue (Dr Shara, another psychiatrist - a person with social status). This line of questioning is supported by Dr Kos, who maintains the new topic through additional maintenance questions. When asked if Linda has found ECT helpful (line 76), Linda again mitigates her response. In other words, although Dr Kos asks for Linda's opinion directly (did you find it helpful), Linda chooses to respond by attributing to a third party, distancing her ownership from the response (*Dr Shara said..*). This is a strikingly passive approach in continuation of the topic.

69. P: (2) = uh do you have any plan at the moment what you would prefer to take if you have to

70. take something in addition to the (1)

71 L: [um Dr Shara suggested um (2) either adding quetiapine (1) or um (3) um (1)

72 . uh a ^course of ECT again^ cuz thats helped in the past sp

73. P: [hum]

[hum]

74. P: = How would you feel about a course of ECT again?

75. L: Um (6) I'm not really (.) sort of worried (.) about ECT cuz I've had it quite a few times already

76. P: // And did you find it really helpful actually or did you

77. L: Um (2) yeah and like the people I was seeing and stuff and Dr Shara has (2) like said it

78. definitely improved [my] mood so

79. P: [uh hum]

80. P: = Have you tried medication (cough) called lamotrigine in the past?

81. L: No

82. P: And there was [cough] also one I (.) was thinking and there's a um uh (1) an amino acid called

83. tryptophan which is also used uh as an anti depressant kind of not like medication but keeping in

84. addition to medication and some people who doesn't get enough nutrition might data might lack

85. of tryptophan and the its really more a kind of supplement than medication so (.) I think we

86. might assess how you respond to Venlafaxine and uh (2) and if you are willing before you start

87. on quetiapine and even during that time adding some tryptophan to your (.) almost to your diet

88. we might see if you respond if you respond better. (1) Are you due to see Dr Shara next ^week?

Time: 35.40

⁵⁹ See chapter six, S. 6.4.2 for further discussion of the role of the psychiatrist

(Asked about the other psychiatrist she sees Dr Rom weekly).

Time: 36.00

89. P: And and she already sent me her assessment so we will keep in touch and uh if you're(.) agreed
 90. I will mention tryptophan in my letter so if she agrees as well then then we might start it (.) its
 91. re::ally (.) very little side effects you will take normally with your food and I would suggest you to
 92. take it just because if you are purging you might not get enough tryptophan and this is the
 93. element (.) which kind of (1) starts a bit later on (1) can't change into body and if you have less
 94. serotonin then you might more likely develop depression as well
 95. L: Ok
 96. P: Yep^? So uh I've made this suggestion you are seeing her next week if you decide at that time
 97. and she agrees you might start on on tryptophan If you f::eel it's not appropriate in your
 98. treatment (.) or if you do not want then (2) and your mood is still quite kind of plateau'd then (.)
 99. you might agree on quetiapine or ECT
 100. L: = OK
 101. P: = and we will arrangement a calling [sigh] so let's meet in two weeks time.....

Time: 37.04

In summary, a strikingly passive stance is being adopted by Linda. There is very little evidence of Linda expressing her own knowledge or experience, choosing not to partake in a more shared conversational encounter. When her preferences or knowledge is expressed, it is done so in a mitigated way to maintain the position of passivity in the encounter. This is especially stark given the content of what is being proposed by Linda at these points. She presents the treatment proposal for ECT and or Quetiapine, without expressing her preference towards either of these options. Both options are associated with significant side effects and ECT is a highly controversial and rare therapy in this context. Throughout, there appears to be no consideration of options, by Linda, about the pros and cons of medication. Linda doesn't directly express her preferences towards medication or any other option discussed in the encounter. There is a strong feeling of helplessness in this encounter and Dr Kos' attempts to move the encounter towards a more shared dialogue fail. On the face of it, these findings are at odds to the interview responses given by Linda in phase one, where there are multiple references to the importance of a sharing of different forms of knowledge in psychiatric medication management encounters. However, perhaps the lack of reference made in the interview to helpful relationships as an important enabler for SDM, is an important consideration for interpretation of these findings. This was, at any rate, a distinguishing factor of Linda's interview, with the vast majority of other participants spending significant time discussing helpful relationships as a key enabler for collaborative psychiatric medication management.

8.3.4. Case 4: Lara.

Lara (female, 42) has received services from the team for a number of months and the recorded meeting is a review meeting with Dr Kos, whom Lara has been seeing approximately once per month. Lara was seeing another psychiatrist, prior to Dr Kos, and this changed when the psychiatrist left the team. A male friend / family member is present with Lara in this meeting. Lara has had her psychiatric medication changed in recent months, and is currently being prescribed Lamotrigine, a mood stabiliser. Quotations from Lara's research interview in phase one are shown on pages 109, 124. In particular, Lara refers to being given a lot of control over previous decisions about her psychiatric medication. Lara is the only participant who refers to being given a list of 7 or 8 options to consider by the psychiatrist, processing and leading the decision herself. However, when asked, Lara stated that at times, she values receiving an opinion from the practitioner and showed a preference towards SDM as an ideal. In the interview Lara refers to the difficulty of processing information when in a crisis and valuing increased guidance during these more difficult times. She also discusses valuing professional opinions and guidance and emphasises the importance of a longer term collaborative and supportive relationship with practitioners, where trust and mutual respect is formed.

This meeting lasts 20 minutes, of which 10 minutes are spent discussing medication and were transcribed. Overall, this transcript gives a different perspective on the decision making process, with Lara taking a far more assertive stance than seen by service users in the other recorded meetings. Lara seems comfortable to express her opinion and at times directs the topic of conversation, using 'treatment questions' and candidate diagnoses through storytelling to assert control in the meeting. The following excerpt occurs at the onset of the meeting.

Time: 0.18

1. P: So how have you been doing since last month?
2. L: Um (.) quite a lot better act::ually
3. P: Very good
- 4.. L: Yeah um I was (.) not quite right for a:ey while and I stepped the (.) the dose to um I
5. think ^three [hundred]^?
- 6.P: [Um yes]
- 7.L: =one of the two little ones
8. P: =YES
9. L: um I've definitely been fe::eling more more myself [
- 10.P: [Very good very good
11. L: [Since I stepped up the dose. Would you agree, yeah^?
12. P: =Very good.

13. L: [OKay. Um, so yeah, I mean I'm still a little but (.) menta::lily (.) um (1) um I feel like
 14: I've ^dropped about fifty IQ points basically^ (laughing)
 15: P: [Oh right]
 16. L: [I'm having difficulty following other peoples convers::ation
 17. P: [oh right]
 18. L: Um I'm (.) um (.) I think my memory is probably worse than it normally i::s
 19. P: =uh hum
 20. L: [Um and I'm a little bit disorg::[anised]and I'm making an effort to (.) pay more
 21. attention to be:ing
 22. P: [uh hum]
 23. L: organised bec[asue thats] very important for my business basically
 24. P: [uh hum] [yes
 25. L: And uh you know I've managed to sort of like keep up with my commitments and
 26. uh not miss out anythi::ng so
 28. P: Great Very good
 29. L: [so thats been OK but yeah I do fe:el (.) fuzzy headed and a bit
 30. blocked but my mood is much improved
 31.P: Very good very good. Do you feel it is much improved because it is more stable or
 32. uh as well so its the fluctuation are the [phone rings] I'm sorry

In this excerpt, from the outset, Lara sets the topic (medication and side effects) in response to Dr Kos' first general question in line 1 (How have things been going?). Lara is quick to offer information without being asked (previous change the dose of medication - lines 4 and 5), thereby taking control and proposing a new topic (medication). Lara then uses a narrative approach to provide information relevant to her experiential understanding and life world. For example, Lara refers to needing to concentrate in her work (line 24). Dr Kos is happy to maintain this topic, with the use of supportive speech gestures (yes, uh hum).

Later in the conversation, Lara often interrupts Dr Kos, sometimes in mid sentence and at times Lara actively disagrees with Dr Kos' proposals. This is shown in the following excerpt:

Time: 13.00

- 133: L: [yes alright (laughing jointly)
 134.P: yes yes oh right yep yep (.) so u::m but still I think because your mood
 135. improved although they are (.) what you mentioned about duh being disorganised
 136. and the problem with the concentration can be st::ill uh the symptoms of th::e of
 137. the of the mood so it still might be still just a bit u:h under uh under normal and and [prese
 138. L: [it feels (?) like that but its not as m::uch under normal as it was last time [I saw you]
 139. P: [yes yes]
 140.L: uh I'm sure the last time I saw you I am probably coming across differently to when
 141: [I last saw you]
 142. P: [yes yes absolutely absolutely
 143. L: = so yeah I think it is better but is it at t:he ^top end of how much^ [you should take]

144. P: [No no its not no its its its still at
 145. least at least hundred milligrams that we can increase to four hundred milligram is
 146. the medically the dose that we recommend but you can go even high::er [because]
 147. there ar::e differences between yeah
 148. L: [O:Kay]
 149. P: = how different people tolerate the medication but at the moment considering the
 150. uh the skin condition and also that your mood is a::lready started to improve I would
 151. leave to the three hundred u::h with a view of increasing if you feel that winter is
 152. coming if the mood starts to dip and is is its again getting u::nstable and you can
 153. increase again [by fifty milligrams
154. L: [yeah ye::ah I don't think I normally have much of u::h much of
155. seasonal [change particularly]
 156. P:= [seasonal oh right]
 157. L:= in that its u:h I've been re:ally really low in the summer [and
 158. P: [summer yeah exactly when we met
 159. L:= so but I don't fe::el that there's a uh there might be a first time use optimus but I
 160. find that I don't have th::at much uh awareness of it because again cuz like my
 161. memory is sh::ot (.) um
 162. P: [but I think again its a vicious circle [so] once you eat
 163. properly you drink properly your memory might simply just improve because you
 164. are not you are h::ydrated and then uh an and and we [
165. L: [ueu (stutter)] [yeah thats possible I mean I fe:::el that I
166. would qui::te like to take the risk of the eczema and go up a bit [if your:::e OK with
167 that]
 168. P: [OH right OK thats that's fine] yeah I agree yeah I'm fine with it [
 169 L: [doctor wool
 170. wasn't [a::ware that I was]
 171. P: [on three hundred] I know I emai:::led I [I sent] yes I
 172. L: [you did]

In this above excerpt, Lara is often claiming speaker rights through both direct interruptions (e.g. lines 138, 154, 169) and the use of questions to change topic and treatment proposals to propose medication changes. For example, in lines 143, 165 and 166 Lara repeatedly suggests increasing the dose of medication and this is done in a unusually direct and unmitigated fashion. In total in the above excerpt, Lara asks three questions (lines 141, 143, 166), which is far higher proportionally than for Carl, Linda or Rosie's transcripts. In addition, Lara appears comfortable challenging Dr Kos' initial suggestions or explanations. For example in line 149 – 153, Dr Kos proposes that it would be useful to leave the medication with view to increasing it, if affected by mood in the winter months. Lara interrupts this speech by Dr Kos (lines 154) by stating she doesn't have seasonal change.

Throughout Dr Kos seems happy for Lara to claim power in the meeting using these strategies, whilst also expressing her own opinion. So, for example, in line 144, in response to Lara asking if the medication can be increased, Dr Kos readily reassures her she is not at

maximum and would be able to increase it, but goes on in lines 149 – 153 to express her opinion for it to remain the same. Lara's disagreement and different 'candidate diagnosis' from lines 154 – 166 results in Lara directly asking to increase the dose, at which point Dr Kos immediately agrees.

In summary, Lara appears to be happy to take a very assertive stance and adopt an unusual number of power claiming discourse strategies.

Further exploration of the contextual information is useful here. In the phase one research interview with Lara, it had emerged that Lara did not feel her initial experience with the pathway and team was satisfactory. In fact it took two to three months after initial referral, and repeated calls / chasing for Lara to see a practitioner. Dr Kos was part of Lara's contact with the team only a few months after this. As such, Lara's unusually assertive approach in this discourse may be partly due to her previous lack of contact with the team. However it is also worth noting that during Lara's contact with the previous psychiatrist (Dr. Percy) Lara was given multiple medication options to review. She had established a relationship with Dr Percy that fitted more with an informed model of decision making.

It is also worth exploring whether the role of the carer/ family member may have been important in this aspect. Out of the four meetings recorded, only Lara brought someone with her to the meeting. The carer's role is explored in the following excerpt, occurring earlier in the conversation, at the point where Dr Kos asks about side effects of medication:

Time: 7.15 mins

46. P: Oh right OK (1) Um ? do you have any side effects on the 300 mg or lamotrigine any
 47. problems at all?
 48. L: Um, nothing that I'm aware of. I mean like I said, I do feel sort of a bit mentally
 49. incompetent and
 50. P: [uh hum
 51. L: but I don't know whether that's down to me or (.) the drugs
 52. P:= yes exactly or or just simply being on the on the on the more
 53. C: [there are something's I mean your
 54. sinuses are kind of playing [up]
 55. P: [U::mm]
 56. L:= ye:ah I
 57. C [I'm guessing
 58. L: [Yeah dry mouth and
 59. C: and your eczema is playing up and you're feeling [nervous?]

60. L: = [Yeah I haven't had eczema since I was an
 61. (.) an adolescent
 62. P: and the eczema has just started again
 63. L: ye::ah
 64. P: [YEAH
 65. L: [and I don't know if that's liable to b::e
 66. P: [It CAN be
 67. L: [Does it make you dry in general my skin is dry my throat is dry my eyes are dry and
 68. you know I think my eczema has come up I don't know if that
 69. P: = I think it might might interfere with the if normally you are vulnerable to the kind
 70. of allergies or even [even] it might it might be the case that its flaring up or it might
 71. be due to something some
 72. L: [eu {stutter}
 73. P: else uh (.) uh I think uh h:ow did you uh tre::at your uh eczema in the past just using uh (1)
 74. L: [Well when I was a child it was very very severe [so it]tended// to be things like
 75. P: [Oh right]
 76. L: having your::e hands covered in tar and then bandaged up [and covered in plastic bags]
 (laughing)
 77. P: [oh my god yes ^(laughing)]
 78. L: [you GO TO SCHOOL and you've got your pencil so it's (laughing) it varied I mean there
 79. was u::h steroid creams and u::m you know (laughing)^ my mum had to tie my
 80. hands and feet to the bed posts so that I wouldn't scratch ^
 81. P: [Oh my god
 82. L: [until I was like you know below the skin
 83. u::m but yeah (.) there was a variety of different treatments

In the excerpt above, in line 53, the carer (labelled as C and emboldened) prompts Lara to talk about her eczema problems. These have not been mentioned so far by Lara in response to Dr Kos's questions. In this context, the additional person in the rooms seems to assist Lara in directing the topic, acting in an advocate capacity at this point in the meeting. Whether this dynamic has resulted in more power claiming strategies being more readily used in this encounter is an interesting possibility to consider.

However in terms of what is discussed, whilst Lara maintains an assertive stance, the topics associated with possible side effects from the medication are nevertheless swept over in this dialogue. Both problems with concentration and memory (mentioned at multiple points by Lara over the course of the meeting) and the skin condition are not seen as directly related to the medication by Dr Kos, and little exploration about possible medication discontinuation as a result of these symptoms is given. Dr Kos indeed steers the conversation away from exploring the possible side effects of medication towards management strategies. For example in lines 70 - 73 (shown for reference below), Dr Kos

both suggests the eczema may be unrelated to medication⁶⁰ and instead directs the conversation towards how this symptom can be managed:

- 70.P of allergies or even [even] it might it might be the case that its flaring up or it might
 71. be due to something some
 72. L: [eu {stutter}]
 73. P: else uh (.) uh I think uh h:ow did you uh tre::at your uh eczema in the past just

Nevertheless, Lara does seem more than happy with the content of the meeting, and later on herself offers her opinion that she would 'prefer to keep the eczema and have good mental health'.

One other aspect of note from this meeting is the rapport apparent in the encounter. In lines 76 - 83, shown in the excerpt above, Lara is retelling the story of when she had severe eczema as a child. Lara then starts to laugh. Dr Kos embraces conversational rules and uses expression to show listening and empathy with the story, Dr Kos also laughs and makes statements such as 'Oh my god' in lines 77 and 81, thereby assisting with the encounter moving more towards a conversational genre. This rapport appears towards the end of the meeting also (see below excerpt), when Lara is more overtly claiming power over topics and treatment proposals.

A friendly conversational stance remains during these more assertive periods in Lara's discourse. At no point does Dr Kos try and reassert power over the encounter through the use of interruptions, questioning, or topic control.

Time: 16.00 mins

- 190 P: lette::r (.) Yes OK uh so can we meet in uh about one month's time again just to
 200. review how things are going with you yes
 201.L: = Um ^I was just wanting to ask you a uh ^que::stion as well do you think um its
 202. like::ly that I'm going to have to stay on u::h psychiatric medication fo:r the rest of
 203. my li::fe o:r for long periods of tim:e or whether I::m going to be:e able t:o tail it of:f
 204. or just how it normally works with people who present like I do~^?
 205. P: = I think^ there's no::rmally we would take these medications like like people take
 206. diabetes so we recommend them to take the medication as long (.) uh as long as it
 207. takes but like with diabetes and special diabetes to people lose weight they might
 208. not need [that] uh uh that uh dose of medication or

⁶⁰ although eczema is known to be one of the common side effects of this particular medication - see Healy 2009, page 110

- 209.L: [uh huh]
210. P: they might come off the medication or with the higher blood pressure medication if
- 211 they lose weight or something in in bi polar disorder what I would say is that the
- 212 lo:::nger you are sta:ble the more likely you will remain sta:ble [
- 213.L: [uh hum]
- 214.P: = in women there are periods of time when they are gettin:g (.) they're vulnerable to
215. increase significantly and this is the time when they are pregnant or definitely after
- 216 delivery so the post
217. L: [uh hum]
218. P parten period they are very very vulnerable [
- 219L: [y::es I remember that
220. P: [yes exactly so
221. within a year they are just rocket high probably the most vulnerable time and als::o
222. the time when when you are reaching um kind of menopause so once you are over
223. the menopause you have been taking the medication you don't have side effects
224. your mood has been stable for long ti::me and you really uh probably would like to
225. come off the medication very gradually probably within kind of (2) couple of months
226. or almost half a [year] you gradually come off the Lamotrigine I think it might be
227. worth a
228. L: [uh hum]
229. P: tri:al at that point so the longer you have a stable mood
230. L: [yeah but that's unlikely to b::e any
231. time soon uh I would say like all the female members of my fam:ily do:nt have
232. menopause until about si::xty
234. P:= sixty oh right. (joint laughing) then if it did occur [but even if
- 235.L: [(?) do you know what I mean
236. P: [in this way if you say after about say two or three years you have about
237. compl::etely stable mood or you are happy with your mood the way it is managed
238. and you feel that you no longer want to take medication (.) you would like to give it
239. a try n(.) the first would be to just reduce whether you need uh a lower dose of the
240. medication actually you don't need this three hundred and fifty uh (.) and and very
241. very gradually reduce the dose and just see whether you would be able to come off
242. it or just stay on like a fifty one hundred milligrams dose for a bit longer .
- 243.L: = OK
244. P: But this point um your mood started to improve you're still a little bit under the
- under normal so I would wait to the point when your mood is (.) normal and count two years
- after that and then then see what is happening [yeah]
- 245 L: [OK]
- Time: 17.30**

In the excerpt above, Lara is claiming power in the conversation through the use of questioning to direct the topic and speaker turn (lines 201 – 204). Lara also frequently interrupts and uses 'but' to rule out and disagree with Dr Kos' previous suggestion of waiting to the end of the menopause to review medication (line 230). Throughout, Dr Kos appears comfortable with the power claiming strategies being adopted and there remains laughter and conversational cues being employed throughout (e.g. line 234). Having said this, Dr Kos' use of a medical analogy is interesting (lines 206 - 211) and may have served

to reinforce the idea of the biological roots of Lara's mental health problems⁶¹, also serving to reinforce Dr Kos' status as a medical prescriber, preserving her social identity. Later in this excerpt, Dr Kos asserts that medication is something for life, or at least the long term, beyond the menopause⁶², suggesting again that there is limited choice over the decision to take the medication. Dr Kos embraces a relatively long narrative through this excerpt reinforcing the message that coming off medication is a slow gradual process, not relevant to consider in the near future. In comparison to the other excerpts then, whilst conversational cues remain, Dr Kos uses more structural affiliations to claim power and reduce open discussion on the topic raised by Lara.

In summary, Lara's recorded meeting provides the most evidence of a shared encounter out of the four cases analysed, both in terms of direct treatment proposals, direct challenges and interruptions in the dialogue, all of which assist Lara in maintaining control over topics and speaker turn. Whilst Dr Kos provides medical opinion and expertise about psychiatric medication, this guidance is influenced strongly by information and preferences presented by Lara. Lara is happy to assert her preferences and frequently offers her experiential knowledge in the dialogue. At the discourse level, Lara also adopts many storytelling / narrative strategies and both participants appear engaged, having achieved a level of rapport, thereby moving the encounter more towards a conversational genre. However, similar to previous cases examined the content of the meeting and what is and (more importantly) is not discussed, suggests only a limited discussion of side effects and options.

8.4. Discussion

All four recorded meetings in this analysis involve the same psychiatrist, Dr Kos, and all occur in the same treatment setting.⁶³ Given the contextual similarities of these meetings, it is perhaps sensible to expect a level of similarity between these dialogues and the discourse cues employed.

⁶¹ . Indeed using physical analogies is mentioned by a minority of practitioners as being particularly helpful when providing information about medication (see chapter seven, S. 7.6 for further details⁶¹)

⁶² although this was then reduced to a period of 2 years *from being stable* as a result of Lara's direct confrontational actions

⁶³ See chapter four, 4.3.2 and chapter nine.

Looking at the content and context of each meeting, certain patterns emerge. There is evidence from these meetings that aspects of the shared decision making process are not fully adhered to. A full or complete set of options are not presented by Dr Kos in any of these meetings. The weighing up of pros and cons and, in particular, the important considerations of side effects, and how these relate to the service users 'life world', is not fully considered in these meetings. There is some evidence that experiential knowledge is valued by Dr Kos in these encounters, and the idea of a 'meeting of experts' applies to some of the excerpts analysed (e.g. see Lara and Rosie).

Looking at the conversational strategies employed by Dr Kos there are also similarities between the meetings. In all meetings, Dr Kos maintains good rapport keeping a similar tone of voice, pace and style through each of the four meetings, only on rare occasions resorting to strategies associated with traditional institutional encounters such as saving face and preserving social identity (e.g. see Rosie, S. 8.3.1. lines 43-50). Dr Kos does, at times become more directive in the decision making process, through the use of treatment proposals and treatment questions, but in general is happy to 'led' by the service user's proposals about medication, when given (e.g. in the case of Rosie, Lara and Linda).

In summary, whilst Dr Kos provides opportunities for several aspects of SDM (valuing experiential knowledge and supporting service user preferences), these opportunities are not always taken up by the service user. In addition, none of these meetings demonstrate a full weighing up of the pros and cons of psychiatric medication and certain information is brushed over by Dr Kos in the encounter. This overview is slightly at odd from the summary of Dr Kos's interview findings. In the interview Dr Kos discusses the importance of service users having ownership and taking increased responsibility for managing mental health problems. Dr Kos sees her own role as presenting a balanced argument for the pros and cons of different psychiatric medication alternatives (see page 143) . She was the only psychiatrist interviewed who disagreed that lacking insight would not prevent a person being involved in decisions about psychiatric medication. As such, Dr Kos appears to value an informed model of decision making, and perhaps more so than her colleagues. However, this is slightly at odds to the findings from the applied CA, in that a full investigation of the pros and cons of medication options was not fully explored. Nevertheless, as mentioned, Dr Kos does provide opportunity for other aspects of SDM (exploring service user preferences) and when opportunities are pursued by the service user (e.g. in the case of Rosie and Lara), Dr Kos is happy to be guided by service user preferences.

There are also large differences in the conversational dynamic between these meetings. In particular, when analysed for power claiming and power sharing strategies, exerted by service users, there is little similarity between the meetings. The four meetings represent a wide spectrum of service user involvement in decision making about psychiatric medication. To represent this idea, the four meetings have been imposed onto the diagram below (Figure 12 - initially presented in the literature review chapter), to show the spectrum of participation observed in the discourse.

In Figure 12 below, Linda's passivity in the encounter may be represented at the foot of the arrow, in the realm of a paternalistic model of doctor patient communication. Carl's dialogue is more similar to *interpretative decision making*, where the 'patient' has the role of presenting as much information as possible, including preferences and opinions, before the doctor suggests treatment. Rosie broadly sit more towards the shared end, exerting treatment proposals and jointly weighing up the pros and cons to reach consensus. Lara's discourse, at times, has similarities with the principles of shared decision making, ie. expressing opinions, valuing different forms of knowledge, building consensus towards a joint decision. However, at other times (e.g. S. 8.3.4. lines 163-170) Lara's discourse is also suggestive of the informed model participation, over riding Dr Kos' opinion and taking ownership of a decision.

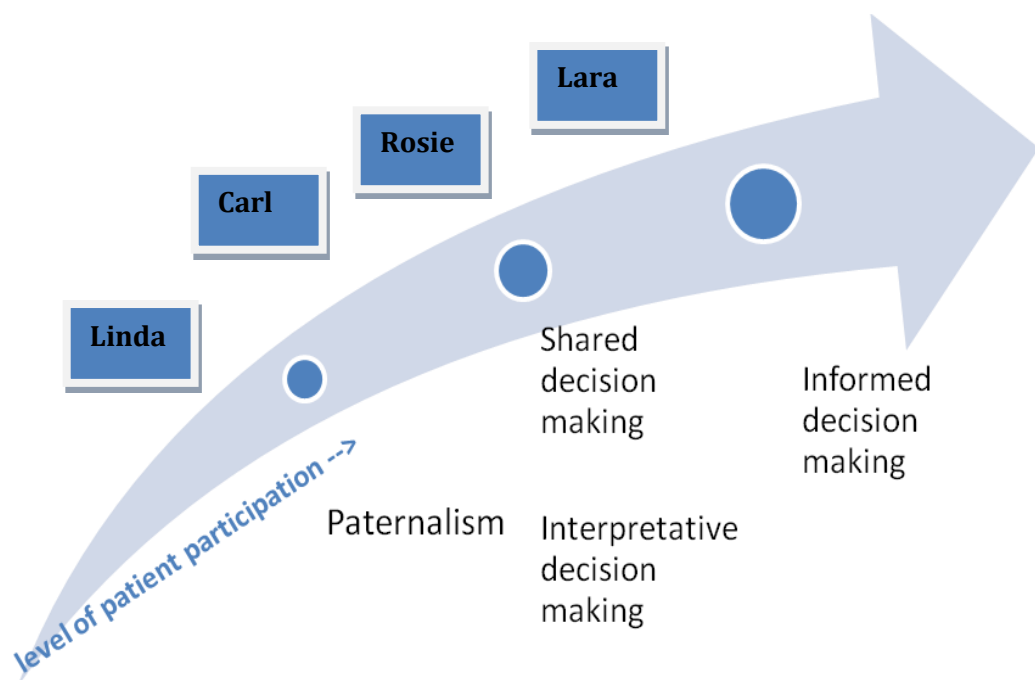


Figure 12. CA Cases imposed on models of doctor - patient decision making.

This diversity in participation is interesting, given the strong institutional norms and power inherently present in this setting. One explanation could lie with the acknowledgement of the importance of service user preferences towards involvement. This is supported, in part, in the re-examination of key themes from the interviews with each of the four service users. For example, Lara discusses valuing a shared approach and is also the only interviewee who mentioned receiving multiple medication options, being left to decide independently. Carl, on the other hand, refers to valuing the psychiatrist and GP taking a leading role, seeing his role as being honest and providing all relevant information. However, Rosie and Linda provide a less straight forward link. Rosie, in her interview, refers to not feeling informed and not having a say or being assertive, yet demonstrates a number of power claiming strategies in the recorded meetings. Linda, on the other hand, refers in the interview, to valuing collaborative approaches which value her experiential knowledge in the decision making process, yet in these dialogues, remains strikingly passive, not, for example, using any narrative or story telling strategies to promote co-constructed topics in the recording.

Another interpretation of this diversity, is the importance of the recovery journey for changes in discourse dynamics. Across all interviews with service users, there was acknowledgement that increased guidance was valued when in a crisis. Processing and retaining information and expressing preferences or opinions was seen by service users as problematic during these more difficult times. At these times service users value increased guidance from practitioners and at times feel less able to take an assertive role in the encounter. Increasing control over decisions and being informed, was seen as a longer term goal and part of the recovery journey. On the face of it then, there is a relationship between stage of recovery and participation in the dialogues observed in this chapter. For example, in the first excerpt, Lara refers to feeling much better and doing well. Lara is happy to assert control over plans for the future and approaches Dr Kos as an expert of medication, but not as holding any particular 'power over' these plans for the future. Indeed, the fact that Lara directly questioned Dr Kos about the long term role of her medication suggests Lara is perhaps farther down the path of recovery and more able to see beyond initial distress. In contrast, it is possible that Linda was experiencing more difficulties when this meeting was recorded, thereby reducing the levels of her participation in the meeting and increasing the value she places on guidance from the psychiatrist. Indeed, at the time of this meeting, Linda was in frequent contact with three psychiatrists from different teams, which may be indicative of current or recent acute problems.

Alternatively, it may also be important to note that, in contrast to most other interviews with service users, Linda places little value on the importance of an ongoing supportive and positive relationship with practitioners, instead focussing on the interactional components of shared decision making. Perhaps the strikingly passive stance adopted by Linda is therefore indicative of not having established a therapeutic bond with a practitioner. This is corroborated by the contextual background, in that it is only Linda's second meeting with Dr Kos.

Regardless of the reasons, Linda's case does present particular challenges for SDM. This dialogue appears a highly asymmetrical encounter, yet Dr Kos does attempt, at times, to move the meeting towards a more shared dialogue also exerting cues which are reminiscent of dissatisfaction with the meeting dynamics (e.g. sighing in line 101, S. 8.3.3). This may link with the concern that emerged from a minority of psychiatrists in the phase one interviews; of feeling a certain pressure from a minority of service users to be 'fixed' or 'cured'. For example, the quote by another psychiatrist in phase one may be relevant to explore:

***Dr White:** but it's also I think the sort of decision making power that she sort of puts with you and sort of tell me what to do, tell me what to take to fix it, and that's a sort of pressure on and I suppose my overall view of this is that this is not the thing that is going to help you the most, but I think it somehow the inability of me to convey that to her maybe because she's quite agitated and therefore it becomes very difficult to have a conversation whose continuously agitated and remain patient I think, There is something about the pressure that anxious people put on you to fix it that really makes it very hard to have that conversation*

Related to this, it may also be important to consider a theme presented at the system level: the increased medicalisation of mental illness and societal expectations of prescribing. In other words structural factors may be important to consider when interpreting cases such as Linda's (and perhaps to a certain extent Carl's), who either prefer or expect a more traditional paternalistic encounter. This may be influenced by the structural dominance of an overly medicalised perspective of mental illness, thereby devaluing experiential knowledge and reducing preferred and actual levels of involvement.

One conclusion that can be drawn from this discussion is the importance of considering both participants (practitioner and service user) in a shared dialogue. Much of the SDM literature is dominated by skills and communication requirements needed by doctors or

medical professionals. The diversity represented in only four meetings explored here, emphasises the need to instead view SDM as involving two participants or '*a meeting of experts*' achieving a sense of what meaningful involvement is for psychiatric medication management practice, and focussing, in particular, on what enables increased control in the longer term recovery journey.

8.5. Chapter summary

In summary, the four meetings have been analysed using an applied conversational analysis, examining power claiming and power sharing cues employed by both participants in the encounter, and thereby exploring how decisions are shared about psychiatric medication in practice. In addition, the use of a case study approach and re-examination of interview data, has enabled increased insight into the challenges and opportunities for collaborative psychiatric medication management.

The four meetings presented show that most participants were happy to employ power claiming cues and Dr Kos, at times, assisted this by employing cues more associated with a 'conversational genre' of discourse. Whilst the encounters remained somewhat asymmetrical given their institutional setting, service users showed multiple instances of directing the topic and speaker rights in these meetings. Often decisions could be considered to be 'shared' by both valuing experiential understanding from service user participants and the medical expertise of the psychiatrist.

Nevertheless the meetings did not conform to the ideals of shared decision making, in that a full set of options were not presented and the pros and cons, especially the consideration of important side effects were not fully considered in these meetings.

In addition, the levels of service user participation varied greatly between meetings. The possible reasons for some of these differences have been briefly discussed. Through exploring this diversity and complexity, a rich conceptualisation of shared decision making for psychiatric medication management is emerging.

Chapter Nine. Discussion

Chapter outline

The chapter begins with a summary of the key findings from the thesis, linking these to models of shared decision making presented in the literature review chapter. The remainder of the chapter explores the diversity and complexity emergent in the data, relating this to relevant empirical research and theoretical concepts. Three levels of analysis are employed to structure the discussion: the interaction, the relationship, and the system.

9.1. Overview of findings

There were two overarching research questions for this thesis:

What are stakeholder views about SDM for psychiatric medication management?

How are decisions about psychiatric medication made in practice?

Looking across findings from phases one and two of this study, broad support for collaborative ways of managing psychiatric medication has been found across all key stakeholder groups. All participants were able to recall examples of positive meetings where decisions about medication took place. In addition there were similarities across stakeholder groups of valuing open and honest dialogues. In part, this was supported by the applied conversation analysis findings (phase two). Here rapport was observed and power claiming activities were frequently asserted by some service users, which were in turn readily supported and maintained by the psychiatrist. The institutional asymmetrical norms of the encounter, at times, were far less apparent and the ideals of a meeting of experts was applicable.

Nevertheless while pockets of best practice were observed in the findings, many barriers to shared decision making emerged. When looking in more depth, a more ambiguous and nuanced approach to shared decision making emerged. A wide amount of diversity and complexity is observed, both within stakeholder groups, between stakeholders groups and across the recorded meetings in phase two.

9.1.1. Linking findings back to models of SDM

Comparisons to transactional models of shared decision making show that the combined findings across data collection phases do not fit well with the established models presented in the literature review chapter. For instance, Charles, Gafni and Whelan (1997; 1999) contend that for SDM to exist, four stages are required, resulting in consensus over the final decision. Other theorists have offered alternative interpretation but retain the priority on transactional requirements for practitioners: offer choice; explore (with the service user) a full range of pros and cons and; consider service user preferences towards participation (Makoul and Clayman, 2006; Edwards and Elwyn, 2009).

On the whole, this data sits outside these prescribed models of SDM in that:

1. Participants reported that relevant information is not always shared, either by the psychiatrist, who delivers minimum levels of information (e.g. side effects), or by the service user (who at times may conceal or withhold clinically relevant information).
2. At times, pressure is applied by the psychiatrist to encourage consensus on a preferred outcome (thus satisfying one criterion for SDM). However, this is not necessarily experienced by the participants as building consensus, but instead is illustrative of a more traditional asymmetrical encounter.
3. Explicit checking (by practitioners) of service user preferences towards active involvement in decisions about psychiatric medication does not emerge in this data⁶⁴

SDM as a model, focused on requirements and actions, may relate well to other medical arenas where, for example, there are several well known treatments with equivalent outcomes and a onetime decision is needed. However, a far more dynamic and interactionally complex picture of service user involvement, shared dialogue, and collaboration in psychiatric medication management has emerged from this thesis.

Instead a broader conceptualisation of SDM is supported by the findings. A non-specific conceptualisation of SDM, where individual decisions are part of a longer-term dynamic process, is highlighted by stakeholders interviewed in phase one. This is similar to models proposed by other authors, for example, Entwistle and Watt (2006), Olthuis, Leget and

⁶⁴ Described as a 'meta' component of SDM.

Grypdonck (2012), Matthias et al (2013) and Moreau et al (2012). In these broader conceptualisations, emotional and affective components of the decision making process were emphasised. For example feelings and views about roles and contributions to the process emerged from the data, suggestive that reflective processes such as feelings of *being in or giving control* and *having an influence* were at the forefront of conceptualisations of SDM. Values associated with medication decisions sitting within the ongoing recovery journey were also illustrated (Corrigan et al, 2012; Deegan and Drake, 2006). For example, promoting service user control, real choice and increased empowerment towards ideals of self management were positively reinforced by participants. Medication decision making as a protracted process of trial and error was also emphasised (Davidson, Miller and Flanagan, 2008). Conversely, support for paternalism and compliance, whilst occurring in a minority of cases, was not a dominant trend in themes from interviews. However there remained a gap between idealised values on the one hand and actual practice on the other.

A high degree of complexity was present in the data, pointing to more subtle and insidious barriers still being prevalent for SDM in psychiatric medication management. It is this complexity which forms the focus of the remainder of this chapter. The enablers of and barriers to meaningful service user involvement in psychiatric medication management practice are presented at the interaction, relationship and system levels of analysis⁶⁵. Many points of discussion emergent from the findings are interlinked and cannot be separated into three clear layers. The layers serve to provide structure and assist with the discussion of the findings.

⁶⁵ the three level onion diagram is used as a framework for presentation and discussion.

9.2. The Micro (interaction) level.

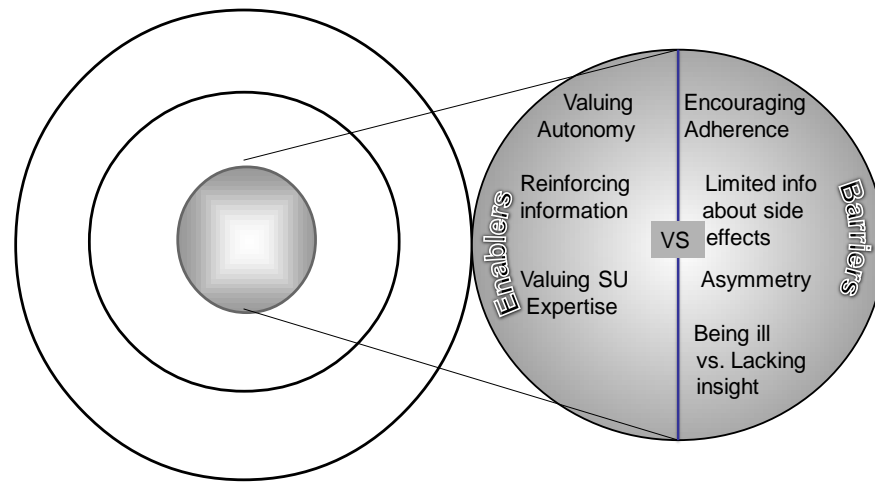


Figure 13. Barriers to and enablers of SDM at the interaction level

9.2.1. Areas of commonality in the data

Firstly, themes emergent across stakeholder groups will be briefly explored, before examining the diversity in findings present at the micro level.

Enabling service users' greater ownership and enhancing control over decisions about psychiatric medication was endorsed by all stakeholder groups in phase one interviews. Additionally, service user input to meetings was seen as important across data sets. In particular, in the phase two recorded meetings, when power claiming strategies were employed by service user's, these were supported and maintained by the psychiatrist, giving the impression of support for the service user taking a more active role in the decision making process. All stakeholder groups from the phase one interviews highlighted the importance of providing information clearly, using clear language and reinforcing information to make it easier for service users to partake in the decision making process about psychiatric medication. The importance of understanding and weighing up the pros and cons of psychiatric medication and their associated side effects was strongly valued by all stakeholder groups. Thus, on the face of it, there was broad positive support for increased service user control, autonomy and choice over decisions about psychiatric medication, with all stakeholder groups suggesting that these factors are conducive to recovery oriented practice and outcomes. Recent research is supportive of this prospective link, finding that regardless of severity of symptomology, the provision of

choice has a strong relationship with recovery outcomes, engagement with services and adherence to interventions (Stanhope et al, 2013; Davidson et al, 2012).

However, the findings from this thesis also point to a gap between the ethical ideals of SDM and actual practice. Broad support for increased service user involvement was found, yet the findings from both phase one and phase two suggest that only a limited presentation of options is occurring. Whilst notable exceptions exist (for example, see Lara's interview where 7 or 8 alternative medication choices were presented in one meeting, S. 5.3.1), the overwhelming flavour of the findings across data sets suggest an incomplete presentation of options and a lack of detailed weighing up of risks and benefits of psychiatric medication in psychiatric medication related discussions.

Provision of information concerning side effects is an important consideration at this point. All participant groups acknowledged that at times, the information provided about associated side effects of psychiatric medication was limited. Similar to previous research, the findings suggest that although service users demonstrate sophisticated mechanisms for gaining knowledge about medication, including using the internet, speaking with peers and other medication experts, such as pharmacists, most referred to valuing the exchange of information in the context of the consultation with the psychiatrists' (Simon et al, 2007; Pestello and Berman, 2008). Yet, in this context, service users often referred to not receiving enough adequate information concerning potential adverse effects for new medication alternatives, and many participants had had previous negative experiences of associated side effects of psychiatric medication. Psychiatrists also openly acknowledged that, at times, information about side effects are only scantily explored. Psychiatrists referred to focussing on secondary symptoms when describing psychiatric medication, often in order to avoid conflict and encourage adherence. In addition, some psychiatrists openly referred to withholding certain types of information that related to longer term or embarrassing side effects. For example, Dr Loh (S. 6.2.2) openly admits his difficulty in discussing sexual dysfunction as a potential side effect.

The applied conversation analysis in phase two highlights the gap between ethical ideals and practice further. The analysis depicted interactions where information on side effects is brushed over by the psychiatrist and where a full exploration of options is not apparent (e.g. see Rosie and the discussion of side effects, S. 8.3.1). The findings are therefore consistent with the literature showing that real choice for decisions concerning psychiatric

medication is limited, often not consisting of a joint weighing up of the risk benefit profile for psychiatric medication options (Matthias et al, 2012; Mendel et al, 2009).

9.2.2. Discordant discourses

9.2.2.1. Valuing increased choice vs. encouraging adherence

The potential reasons for the discrepancy between the values of choice and autonomy on the one hand and actual practice needs further investigation. This discordance is reminiscent of Seale et al's (2006) study into psychiatrists' experiences where such a paradox was also observed⁶⁶. In addition, recent research has also found juxtaposed discourses (by family doctors in Canada in treating depression) of doctor influence, professional judgement and expert knowledge alongside service user autonomy and ownership of decision (McMullan, 2012). In explanation it has been suggested that psychiatrists strongly value the role and evidence base for medication, which largely excludes the service user's experience of taking medication (Chaplin et al, 2007), and that *this is likely to reflect the view, based on training and research, that taking medication is in people's best interests* (Baker et al. 2013; p. 4). Thus this data indicates that components at the system or structural level may hinder open and honest dialogue from emerging. For example, McMullan (2012) concludes that:

...[the] taken for granted nature of patient choice in treatment decision making can be seen as paradoxical: a state of being [depression] that has become increasingly medicalised and, by definition, under the authority of the physicians, from the viewpoint of the family physician, is ultimately under the authority of the patient. ...is this construction of decision making understood as a balance of power between physician and patient?

(ibid, p.247)

It has been suggested that the two discourses of choice and autonomy alongside judgement and expert knowledge do not necessarily prevent shared decision making (Karneili-Miller and Eisovits, 2009). For one psychiatrist, this emphasis on service user ownership and control was promoted even when a service user was deemed to lack insight⁶⁷ into being ill.

It's not about insight, I think if someone hasn't got an insight and I feel that very strongly he suffers from a mental illness he needs to take medication, again it would be a decision made by him, if he doesn't want to take it, he doesn't take it.

Dr Kos, S. 6.2.4.

⁶⁶ See Literature review chapter for further details of this study

⁶⁷ See S. 9.2.2.5 for discussion of lack of insight as a barrier to involvement

Thereby suggesting that valuing medication, in of itself, should not prevent the service user being at the centre of the decision making process or take away from the control or ownership over the decision. However the findings from phase one interviews also suggest that both practitioners fear and service users acknowledge that painting a picture of false compliance to 'keep the peace' is still an option, thereby highlighting a lack of trust in the encounters. Indeed this false compliance scenario was deemed as a particularly concerning aspect of medication management practice. It was often used to conceptualise examples of negative meetings by both service users and psychiatrists in the critical incident section of research interviews⁶⁸, being illustrative of the deeper underlying problems of both not having formed trust in the longer term relationship and maintaining face in the encounter (Seale et al, 2006).

9.2.2.2. A spectrum of participation

Nevertheless, across both data sets, there remained a wide spectrum of participation by service users in decisions about psychiatric medication. For phase two, a spectrum of participation is apparent across the recorded meetings. This is especially striking given that the same psychiatrist was present in all four meetings. Nonetheless, this diversity also emerged from the interview data, within each of the stakeholder groups. The complexity of the situational specific context of the meeting, both in terms of the service user preferences towards participation, their current state of wellbeing and distress at the time of making a decision, the therapeutic alliance, as well as the psychiatrist's background, style and approach point to a wide range of involvement happening in medication management practice. Models such as Quirk's spectrum of pressure are useful to consider at this point (Quirk, 2007; Quirk et al, 2012). Quirk proposes a typology of pressure ranging from 'open decisions', akin to aspects of a concordant relationship through to 'pressured decision making', reminiscent of more coercive practices⁶⁹.

Drawing on this work and the related research of Seale, Chaplin and Lelliott (Seale et al, 2006; Chaplin et al, 2007), Table 10 below presents findings from this thesis as a typology of potential involvement⁷⁰. The typology presented aims to represent the diversity in participation observed across the data from stakeholder groups, constructing shared

⁶⁸ For example, see Dr Loh, S..6.2.4

⁶⁹ See Literature review chapter for further details

⁷⁰ Quirk (2007) also presents the term 'tactful manipulation' which has been adopted in the description of the 3rd typology proposed from this data.

medication management practice in mental health⁷¹. Each type is presented as a hypothetical typical example interaction. To note, while similar, the typology presented in table 10 is qualitatively different from the afore mentioned work of Quirk and colleagues, which predominantly focuses the psychiatrist's perspective and actions⁷².

Type of involvement	Examples
<i>Active self management</i>	Service user adopts active power claiming strategies in conversation, asserting opinions and preferences and asking questions (e.g. see Lara's recorded meeting – S. 8.3.4). Prescriber assists process and provides information on pros and cons, being led by service user preferences. Final decision deferred to service user, who asserts preference then and there or following full review of relevant information (e.g. Lara's interview, S. 5.6.2, Dr Percy's interview, S. 6.2.1, CPN Mark, S. 7.2.1).
<i>Shared</i>	Discussion and dialogue over possible options and pros and cons of a new medication or coming off medication. Psychiatrist presents opinion on best course of action, but in consideration with service user. Service user brings experiential expertise to the meeting and this is reflected upon in the encounter. There remains a conversational style with little asymmetry (e.g. Dr. White, S. 6.2.1, 6.5.2, Dr Black, S. 6.3.1, Holly and Lara S. 5.6.2)
<i>Tactful manipulation</i>	Psychiatrist steers patient towards new medication, possibly avoiding concerns raised about side effects (e.g. Rosie's recorded meeting , section 8.3.1). Service user, whilst participating in conversation and at times direct topics in conversation, happy to be led by psychiatrist expertise on final decision. No objections raised and mutual consensus (e.g. CPN Heather and Elsa, S. 7.2.2, Carl, 5.6.2, Dr Bloggs, 6.5.2).
<i>Fractured passivity</i>	In one offshoot of this typology, the service user remains overtly passive in conversation and avoids opportunities to direct topics or assert preferences towards goals or problems to be discussed. A sense of helplessness emerges. (e.g. See Linda's recorded meeting, 8.3.4). Psychiatrist uncomfortable and unsure how to progress conversation (see Dr White, S. 6.2.3).

⁷¹ CPNs are directly mentioned less in this part of the discussion. Reference to specific meetings about psychiatric medication often centred around prescribers (psychiatrists only in all cases locally in this setting) and service users. However thematic findings from CPN data forms part of the typology presented

⁷² In Quirk et al's (2012) article the service user's actions are considered in the analysis, but with more emphasis on either agreement and or resistance to the psychiatrist actions.

	Another scenario in this typology is if the practitioner deems the service user to lack insight into being ill. The practitioner is unlikely to explore range of options and embarks on tactful manipulation above (e.g. Dr. White, S. 6.2.4). The service user may be less willing to express their views, may adopt more subversive strategies and 'false compliance' is a possible outcome (e.g. Dr. Black, S. 6.2.1. Terry, S. 5.5.1)
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Table 10. Typology of service user involvement, across data sets

Notably, unlike Quirk (2007), findings did not emerge that fall into a typology so named 'pressured decision making', where the service user actively resists and the psychiatrists 'presses on', falling more towards the ideas of overt coercive encounter (p. 310). This is likely to be related to contextual differences between the studies. Most notably, this study has been conducted in a treatment setting where people are likely less likely to have received coercive practice and problems associated with historical institutionalisation are rare (see chapter one for further description).

In its place I refer to the typology I have labelled '*fractured passivity*'. This term has been adapted from the recent work of Margaret Archer (Archer, 2012), a British sociologist, who has explored social identity and the role of reflexivity in the relationship between human agency and social structure. Archer uses the term *fractured reflexivity* to describe one of four modes of reflexivity *practised by all of us, including in the internal conversation we hold with ourselves* (Archer, 2012, p. 12). She defines it as taking place *when internal conversations cannot lead to purposeful courses of action, but intensify personal distress and disorientation resulting in expressive action* (Archer, 2013, p.13). This term was adapted for its poignancy, suggestive of those meetings where there is no orientation towards purposeful action by service user and a lack of reflexive response to opportunities, indicating a suspension of personal power.

The spectrum seems to link well to established ideas of agency and participation in the literature (e.g. see Tritter and McCallum, 2006; Gabe, Bury and Elston, 2004; Arnstein, 1969), highlighting how different aspects of agency are available to service users in the encounter. Thus, these findings point towards a need to explore the dynamic process further. In other words, why is such a spectrum of involvement observed in this data?

There are various ways in which an answer to this question could be approached. The argument could be presented that individual differences in service user preferences to participation and decision making are important to consider. The recent and ongoing work of Puschner et al (2013), in the pan European CEDAR study has developed measures to explore clinical decision making style (CDMS) alongside involvement and satisfaction scales (CDIS) to measure service user and practitioner preferences towards participation. A few observations from this study link to the discussion of the diversity found in the data. The findings from the initial phases of the CEDAR project indicated that a majority of service users prefer shared (as oppose to passive or active) participation and wish for a high level of information (as opposed to moderate requirements expressed by practitioners) (Pushner et al, 2013). This fits with a sub theme emergent from the qualitative data from interviews with service users; the importance of timely, accurate information, especially for side effects, delivered in a way which is easily accessible and personalised to the situation at the time. In the Pushner et al (2013) study, a *preference for participation* was shown to be a trait like stable component of the person influencing preference for decision making style, supportive of previous research which has also found stable demographic differences in individual preferences of participation (Say et al, 2006; O Neal et al 2008; Hamann, 2005). However, the sub scale, *preference for information*, was separate to the participation component of the scale and positively correlated with stages of recovery measures (e.g. STORI model; Anderson, Oades, Caputi, 2003; 2006). This thereby suggests that preference for information may be particularly and positively related to stages of recovery with aspects such as desire for increased control and self management being less applicable to consider as a stable individual difference.

Hence it appears that the typology, rather than just an underlying stable preferences towards participation style in an encounter, may also relate to what stage a person is at in their recovery journey. This impacts on preferences about how much information a person desires and feels able to process at a specific time. Indeed there is a conceptual overlap with the typology presented and the validated STORI model⁷³ (Andresen, Caputi, Oades, 2006). In particular, the stages of moratorium (stage 1) map onto the fractured passivity, associated with hopelessness and withdrawal, and the active self management typology links with the later stages, 4 and 5; rebuilding and growth. Of note, such models give an impression of linear progression through stages, which is potentially misleading.

⁷³ See chapter three for further details of this model

But if viewed as a typology, with overlapping and qualitatively different components, this connection is potentially useful to consider in exploring the diversity in the data and ideas of an iterative journey, over time.

The typology may also link with ideas of the process of recovery and the consequential changes in identity. Buck et al (2013) suggest that the recovery process itself creates challenges and a sense of loss alongside the acceptance of agency. The typology 'fractured passivity' may therefore represent challenges associated with the acceptance of agency in the recovery journey. By accepting agency, there may be experience of no longer being unique and losses to previous sense of identities, or making meaning of the world. *'At times the return of a sense of agency empowered him, but at other times it was terrifying and filled him with anxiety and uncertainty, particularly when he struggled with reclaiming his identity'*. (Buck et al, 2013, p. 138).

9.2.2.3. Valuing guidance in a crisis and the importance of reinforcing information

A strong theme from interviews with service users in this study was that a key barrier to being involved in decisions were the problems of being able, in a crisis, to process information, as well as increasing problems with communication and expression, impacting on how involved it was possible to be. Clear communication and the need to reinforce information during these more difficult times was recognised by all, so that the service user may consider the options fully. Providing multiple methods of information provision, but with an emphasis on clear communication about the pros and cons in the context of a conversation with the practitioner, was valued, as was the need to revisit information. For service users, a particular emphasis was placed on valuing guidance from the practitioner during these more difficult times, but in the context of a longer term relationship⁷⁴. This sat alongside the ideals of the longer term goal of increased control, awareness and self management in the medication management process. The value placed on reinforced information during these more difficult periods was seen to enable feelings of increased control. Many participants referred to specific tools, such as a written letter in follow up to the meeting, provision of additional leaflets and access to online resources, enabling the service user to 'revisit' the information. Also the use of advance directives, crisis plans and establishing views and preferences towards medication was seen as

⁷⁴ See relationship level, S. 9.3 for further discussion

possibly helpful for involvement, during these more difficult times (although to note, advance directives did not emerge as common practice). The findings therefore support literature which has shown decision aids and reinforcing information may be of particular importance to assisting service user involvement during more difficult periods (Hamann, 2006; 2011; Duncan et al, 2010; Drake et al 2009; Ben-Zeev et al, 2012). The value placed on dialogue and receiving information in the context of existing relationships points to coaching as a tool as particularly relevant for medication management practice (O Connor, Stacey and Legare, 2008; Coulter and Ellins, 2007). Regardless of approach or strategy focused upon however, according to Coulter and Ellins (2007) in the review of this literature *'health information materials, decision aids...and other technologies or patient engagement are most effective whether they supplement, rather than replace, interactions between patients and professionals* (ibid, p.27).

In summary, these findings point to all stakeholder groups valuing the ideals of medication management operating within a recovery oriented practice. 'Hope, agency and opportunity', as guiding principles seem widely supported by these findings, yet as mentioned above, there is nevertheless a significant gap between ethical ideals and actual practice (Shepherd, Boardman and Slade, 2008; RCPsych, 2010; Ranz, 2008).

9.2.2.4. *An asymmetrical encounter*

Differences between service users conceptualisations of SDM as compared to psychiatrists and care coordinators are worth consideration. Service users often describe feeling patronised, feeling like a child and being spoken down to. This points to the perception that the doctor knows best as still common in modern day psychiatric practice, together with an explicit notion that users of services may not have the capacity to decide for themselves, or that their understanding of the situation is not valid (Zisman-Iliani et al, 2013). Psychiatrists were less likely to acknowledge these barriers in the interviews. This points to an asymmetrical encounter between the psychiatrist as the prescriber and the service user as recipient. The asymmetry is touched upon in chapter eight⁷⁵, although as discussed above, a slightly more complex picture emerges, instead suggesting that service users, at times, feel able to embark on a far more assertive stance in the interaction and that, at least for this psychiatrist in this study, this was supported in meetings.

⁷⁵ The applied conversation analysis for phase two recorded meetings

9.2.2.5. Being ill vs. lack of insight

A second but crucial difference between stakeholder groups in the data concerns how illness symptoms are conceptualised. As mentioned above, all stakeholder groups mention that being ill or in crisis hinders involvement. But psychiatrists and to a lesser degree CPN care coordinators frequently emphasise that a lack of insight, perceived as a deficit, is a key barrier to service users engaging in collaborative dialogue. Practitioners acknowledge that when working with a person deemed to lack insight into being ill, communication style may change, less information is provided, and at times discursive practices are used that could be described as subtle forms of persuasion (Chaplin et al, 2007; Seale et al, 2006; Quirk et al, 2012). For service users on the other hand, lack of insight was not mentioned frequently as an important barrier to full participation in decisions about psychiatric medication. When, it was mentioned, lack of insight was not prioritised as a particular barrier over other issues. Instead, the emphasis is on the impact of increased distress and lower levels of concentration and other cognitive functions such as memory and motivation, as being by far the biggest challenges to both feeling involved and fully participating in a shared and open dialogue. These may be consequences of either the illness itself, or side-effects of taking medication, although the latter appears not to be recognised as a barrier to SDM by practitioners in the interviews.

This discrepancy needs further exploration. Recent research by Wei Wen Chong et al (2013) has also highlighted differences in perceived barriers of SDM related to notions of competency and insight. This study, which undertook qualitative interviews with both general health and mental health practitioners, including medical practitioners (psychiatrists and GPs) as well as pharmacists, nurses, psychologists, occupational therapists and social workers, found that only mental health practitioners frequently perceived a lack of competence to be a primary barrier to shared decision making, whereas clear information provision was highlighted by all as an important enabler. Lack of insight, as a perceived barrier to SDM, is particular to decision making in mental health settings, most of which revolve around psychiatric medication (Moncrieff, 2009). In addition and according to my data, this view is emphasised by practitioners, as opposed to being a more general concern shared by service users, indicative perhaps of wider negative attitudes towards mental illness by professional groups (Hansson, 2013).

Nonetheless, despite practitioners' reservations, insight into illness should not, in itself, be seen as a pre-requisite to engaging in SDM. In the literature review chapter, research was

presented which showed that service users are capable of participating in most decision-making situations (Loh et al, 2007b). When additional support is required, recent research has suggested that training in 'meta cognition' may assist with increasing levels of service user involvement in decision (Chan and Mak, 2012). This is in addition to the research which has conversely found a relationship between 'having insight' and more negative outcomes for mental health, suggestive that acceptance of a diagnosis may in fact be related to issues such as internalised stigma, which in turn are detrimental to longer term prognosis (Lysaker, Roe and Yanos, 2007).

'Lack of insight' so termed by the practitioners in the findings, whilst being described as a symptom of the mental health problem in question, could also be seen as a '*symptom*' of the wider system and one tool in the existing power structures of a psychiatric system dominated by overly medicalised perspectives. One of the implications of this finding is linked to the ideas of having 'capacity' to make decisions. According to Davidson et al (2012b):

'...by viewing patients as unable to make their own decisions, set their own goals, or pursue their own dreams, until or unless they have recovered. However one of the several important things missing from such an approach is any recognition that making one's own decisions, setting own's goals and pursuing one's own aspirations are all crucial components of the recovery process itself. By discouraging this, mental health services have unfortunately relegated the person to and kept him or her trapped within a passive, dependent, disabled and despondent role.'

(ibid, p. 85)

9.2.2.6. Service User Knowledge vs. Medical Expertise

The emphasis placed by practitioners on lack of insight as a barrier may then instead point to experiential knowledge as present only at the periphery of the decision-making process, and diagnosis, labelling and *othering* at the fore. According to Zisman - Iliani et al (2013, pp 151-152) there is a *bias in psychiatry that persons with serious mental illness cannot be reliable reporters of their own experiences and that they cannot be valuable contributing partners to research, treatment, diagnostic processes*. This is mostly represented in the findings by consideration of individual experiences and how these are explored in the context of psychiatric medication management decision making. It should also be noted that collective experiential knowledge that is built over time in groups, is also not referred to in these findings (Borkman, 1999). There appears both a lack of critical group reflection from practitioners, in that this did not emerge as common practice by practitioners in the

interviews. In addition, there was little or no mention of service users groups⁷⁶ or collective mechanisms of involvement. In fact, I was keen to explore the role of medication support groups, but none were operational at the time of the study. An overly individualistic approach to mental health services in the UK, as compared to other EU countries, may explain these observations (see system level, S. 9.4 below).

Finally, another emergent difference in themes between stakeholder groups relates to emphasis placed on the importance of service user knowledge and expertise. Service users alongside CPNs were seen to emphasise the importance of valuing service user knowledge and expertise. This was less the case for the psychiatrists interviewed, who instead placed more emphasis on giving choice, handing over control and presenting information in a balanced way⁷⁷. These differences and the possible reasons for them are also explored below, at the relationship and system level.

9.3. The relationship level

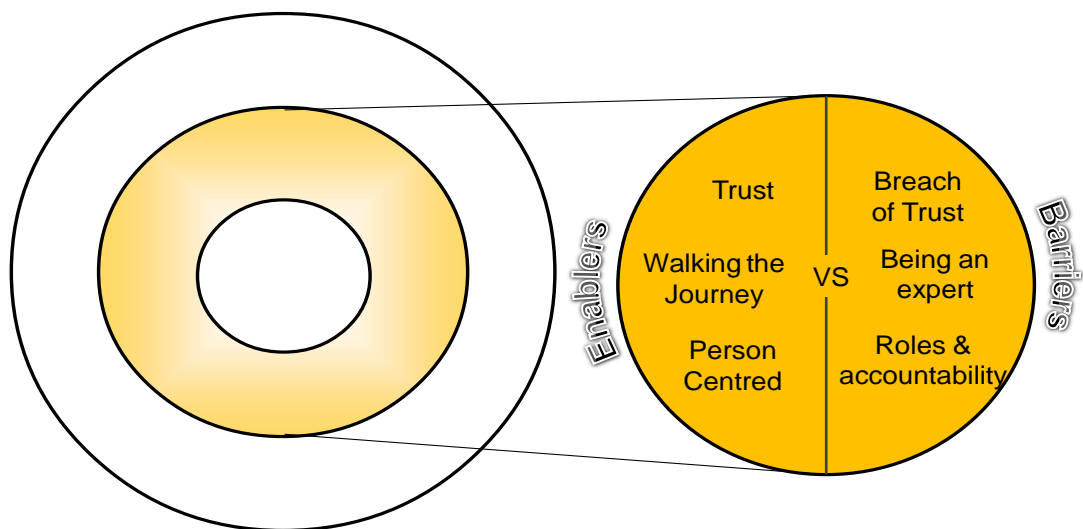


Figure 14. Barriers and enablers at the relationship level

⁷⁶ To note, some SU participants did mention informal relationships with other peers as helpful

⁷⁷ See S. 9.2.2.1 above - Valuing increased choice vs. encouraging adherence

At the relationship level, enablers (left hand side of circle) and barriers (on the right hand side) are presented in Figure 14 above.

The findings highlight the enabling role of the therapeutic relationship for ensuring continued and increased levels of service user control and ownership in medication management practice. All stakeholder groups refer to the establishment of trust as central to a meaningful shared decision making process for psychiatric medication management. Trust was seen to enable honest open dialogue which in turn enabled increased involvement. It would appear that the establishment of a relationship plays a helpful role in the negotiation process for psychiatric management, both by encouraging the service user perspective to be better understood and through impact on open and honest dialogue. These findings support previous research which highlights the importance of the therapeutic relationship (TR) for service user control and increased agency over decisions (Simon et al, 2007; Davidson, Flanagan and Styron, 2008; Davidson et al, 2012; Street et al, 2009; Farelly and Lester, 2014; Stanhope et al, 2013). In Stanhope et al's (2013) study, the therapeutic relationship played an important role in the impact of choice on recovery outcomes. According to the authors *decisional conflicts or disagreement could be understood differently and have different outcomes, if they occur within the context of a trusting relationship between the service user and psychiatrist* (ibid, p.199).

The findings from phase one interviews also point to differences in how relationships are conceptualised by different stakeholder groups. Service users and most CPNs highlighted the importance of supportive nurturing aspects of the relationship, where 'knowing' the service user is at the fore. CPNs and service users refer to walking the journey together and formation of a partnership, where there is joint reflection on the recovery journey. Supporting service users through difficult times and celebrating success was also mentioned, in addition the importance of genuinely caring about the service user. These aspects of the TR were seen to buffer against problems of fully weighing up option and processing relevant information during periods of crisis. In these situations strong TRs were helpful through the acknowledgement that increased guidance was likely, but also as a way of tackling institutional stigma in the system (Denhov and Topor, 2011). 'Walking the journey' aspects of the TR were mentioned far less by psychiatrists, who instead viewed the role of the psychiatrist as providing expertise and advice to service users.

At this point then, it is relevant to consider the differing roles of psychiatrists and CPNs in the conceptualisation of therapeutic relationships.

9.3.1. Walking the journey vs. Being an expert

A dilemma for psychiatrists is the tension between the value placed on ideals of choice and self management for recovery but acknowledging their role as being 'the medication expert'; consultative and wielding power. Psychiatrists are the prescribers⁷⁸. In interviews with psychiatrists, the majority refer to recent changes in organisational structure impacting their role in psychiatric medication management, moving away from overseeing treatment and establishing long term relationships with service users, towards performing a more consultative role. Psychiatrists often were not seen to offer continuity of care but instead act as more remote experts.

This is an interesting observation and does on the face of it present challenges towards the ideals of shared decision making which is built on the foundation of different forms of knowledge having equality and a 'meeting of experts' being applicable. For example, Fukui et al (2013) found that the incorporation of service user's perspective and preferences was the most important factor related to achieving agreement in an encounter. In order to encourage increased SDM, Roberts and Wolfson (2004) have emphasised a shift from staff who are seen as remote, in a position of expertise and 'authority', to the position of a personal coach or trainer: *"offering their professional skills and knowledge, while learning from and valuing the patient, who is an expert by experience"* (ibid, p. 38).

Whilst in of itself, these observations do not limit the possibility of such an encounter, a lessening of continuity of care and longer term relationships with service users and psychiatrists is likely to reinforce structural power in the encounter and a greater asymmetry, where medication information is withheld, options are not discussed openly, and where service users feel threatened and unable to express themselves. The timely review by Farelly and Lester (2014) is also indicative of these challenges for achieving person centred approaches to care. The authors suggest that broader social and policy factors are associated with practitioners *exerting control and limiting service users opportunities for service users to self determine* (ibid, p.9). This is an under researched area. Some previous research suggests continuity of care is a particular concern for service users (Laugharne et al 2011; Noyes et al, 2011; Rose et al, 2009). However while some psychiatrists interviewed acknowledged the challenge of these changes, some positive implications were also expressed. These included links to increased personalisation and

⁷⁸ In this sample, some CPNs were also 'non medical prescribers'. However in the interviews conducted these skills were not being utilised. Only psychiatrists or in a small minority of cases, GPs were prescribing psychiatric medication.

self management in mental health services and giving the service user more control, as for example described by Dr. White in section 6.4.2. *the patient has to see what the added value is..not just my view, it's also what's the patients view, is there anyone else that could potentially do that just as well.* Hence from this perspective the changing role of the psychiatrist may also enable the service user to take more ownership and increased control over the wider services they receive, deciding who is best placed to provide support. These values link well to the current and ongoing changes occurring across health care. For example, the Royal College of Psychiatrists released a statement in support of the introduction of personalised health budgets in March 2013 (RCoP, 2013). Repper and Perkins (2003) have neatly summarised this change to professionals being, *"on-tap, not on top"*. It implies a very different power relationship between professionals and the people they are there to serve. This also links to the related trend towards the GP being at the centre of a person's experience with the mental health system alongside increased provider and treatment choice. While personalisation is part of the wider economic neo liberal agenda, it also has the aim of encouraging greater service user control in interactions with mental health services. (DH, 2012b; 2010;2009).

Nevertheless, there remains an incongruence between values of increased control, personalisation, choice and ownership, and the strong emphasis placed by service users and CPNs of knowing the service user, building trust and support in the building of a longer term therapeutic relationship. Indeed, Mind's (2012) publication reflects on these issues in their response to the huge transformational change underway throughout the NHS. The following quote is from Mind's recent response to the government's second consultation document under the title 'no decision about me without me' referring to the changes towards providing choice in provision of GPs (Mind, 2012).

Building this trust and creating a stable doctor-patient relationship is a result of long term contact with the same practitioner over numerous appointments....in general the ability to register with different GP practices is not a priority for people with mental health problems if they have spent many years building a trusting relationship with their GP.

(Mind, 2012, p.12)

9.3.2. The therapeutic relationship and the role of the CPN?

These concerns withstanding, this study highlighted many positive illustrations of relationships with psychiatrists and other practitioners, including GPs. No one ideal style or a list of competencies were described, but instead positive descriptions emerged of a

dynamic process over time with a joint formation of trust, respect, but also support understanding and listening as important elements. This was supplemented by service users' descriptions of 'going above and beyond the call of duty'. This was seen as particularly poignant of a positive relationship with a practitioner, but interestingly has only received scant attention in previous research (Denhov and Topor, 2012). In addition, as mentioned above, the importance of 'knowing the person' was seen as especially helpful during more difficult times when more guidance was seen as necessary.

The role of the psychiatrist and the move towards increased responsibility of GPs in medication management practice has briefly been explored. Given these findings, it is also important to explore the potential supportive role of the CPN in the medication management encounter.

As discussed CPNs, often alongside services users, place importance on 'walking the journey together'. For the majority of service users, the practitioner knowing the person and seeing them over time in the journey of recovery with the CPN (or other practitioners) was a hugely helpful and enabling aspect for involvement in decisions about medication (e.g. see S. 5.4.3, Natasha). As mentioned the TR is a key enabling component for SDM, buffering against the challenges presented at the micro and macro levels of analysis. There is well established literature exploring the characteristics of helpful / therapeutic relationships and person centred approaches to care (e.g. Carl Rogers, 1902 - 1987). For community mental health service provision there is a growing interest in the components of TRs and its links to concordance (e.g. Farelly and Lester, 2014; Davidson, Miller and Flanagan, 2008; Borg and Kristiansen, 2004; McGuire - Sniekers, et al 2007; Thompson and McCabe, 2012; Denhov and Topor, 2011; Laughorne et al, 2011). Components of strong TRs emphasised by service users and CPNs support the previous research which have highlighted the importance of; ongoing reliable support through regular contact; active listening, and; the process of 'really knowing ' the service user, through repeated interactions. These components enable practitioners to help support service users in decision making during these more difficult periods (Kirsh and Tate, 2006; Laughorne et al, 2011; Markwick, 2013). Markwick's framework for recovery oriented relationships is particularly poignant here and is supported by the CPN findings. The framework incorporates the themes: walking the journey, tough love, panning for agency and finally, letting go. Sitting within each of these characteristics practitioners need to hold a belief in a person's ability to develop and recover as well as hold a *genuine curiosity in the developing relationship* (Markwick, 2013; p.10).

However, in addition, CPNs also discuss acting as the go between or advocate for the service user with the prescribing doctor. Thus findings support the notion of *knowing the person* in the nursing role, although this does come with particular demands. For example, it could also be superficial and might lead to a self fulfilling prophecy. The demands of so called *toggling* between the professional and ordinary identity, as laid out by Barker et al (1999; p.280), may be particularly difficult in the context of medication management practice. Indeed research has suggested a creation of 'us and them' and movement away from person centred aspects of nursing practice in other health care contexts (Barker et al 1999; Bolster and Manias, 2010). Thus the importance of the CPN in the medication management process may be a double edged sword: On the one hand, CPNs reference to acting as the go between may in itself add distance to the control and agency of the service user, instead allowing for dominant structures such as the medical expertise and resultant *othering* issues to propagate, thereby further distancing service user knowledge and expertise to the periphery. On the other hand however, the CPN interviews indicate a sub theme of passion within the transcripts, of a real desire to walk with the service user on their recovery journey. This may actually serve to bring the service user perspective more to the fore of decision making for psychiatric medication management, both through the reduction of stigma and *othering* and through advocating on behalf of the service user to the more distanced psychiatrist. It may then that critical reflective practice may be particularly important for this aspect of the nursing role to be realised. This would, at any rate, be an interesting avenue for further research to explore.

Finally, the importance of other relationships are also implicated by the findings, both as part of wider services (occupational therapists, psychologists, pharmacists, peer support workers) and beyond (family and friends, community support groups etc). The introduction of peer support workers are of particular note (Repper and Carter, 2011). The ImROC (see chapter one) suggests that the introduction of peer workers may, in addition to providing hope and inspiration to service users and promoting recovery, also challenge negative attitudes of staff and bring the service user perspective more the fore of decisions about psychiatric medication (Pitt et al 2013; Repper, Aldridge and Gilfoyle, 2013). The findings are also congruent with approaches that emphasise open dialogue as a form of treatment, where wider therapeutic networks may assist in ongoing negotiated decisions about medication (e.g. the Open Dialogue approach, see Seikkula et al, 2006).

9.4. The macro level

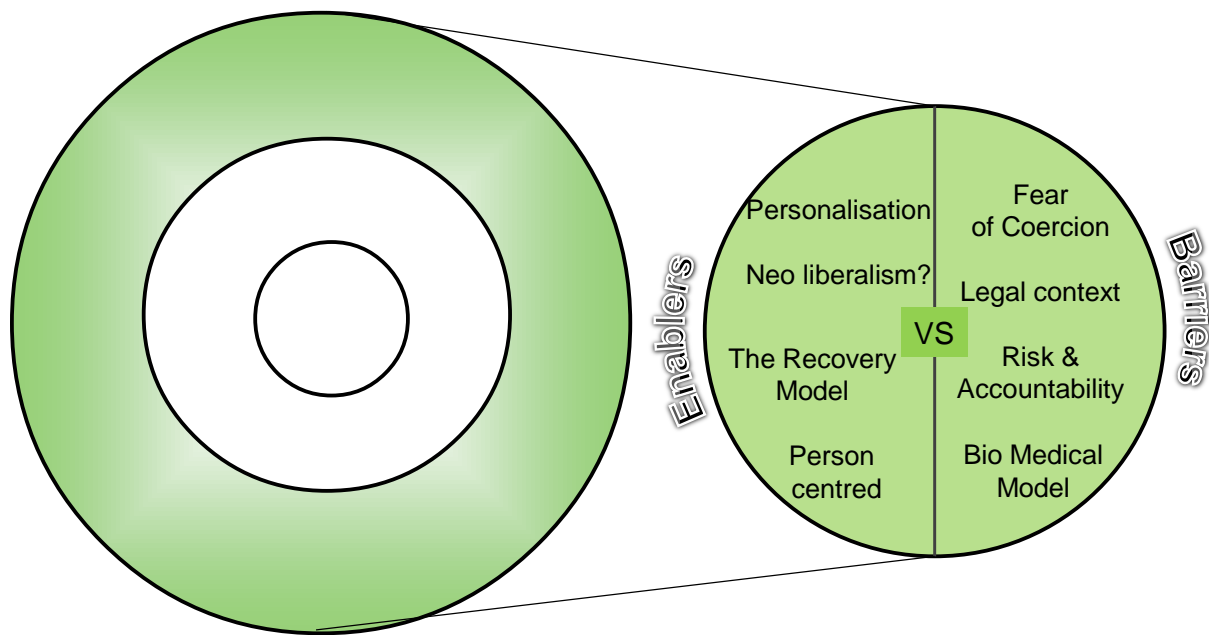


Figure 15. Barriers and enablers at the macro level

Thematic findings from the interviews and observations from the applied conversation analysis data point to challenges at a system level of analysis, which map onto more hidden forms of power as key challenges for the psychiatric medication encounter.

9.4.1. A second face of power

In the recorded meetings phase, the applied conversation analysis reveals how a full or complete set of options are not presented by Dr Kos in any of the meetings. The weighing up of pros and cons and particularly the important considerations of side effects and how these relate to the service users 'life world'⁷⁹ is not fully discussed in these meetings and at times Dr Kos was found to take a more directive role in the encounter, offering treatment proposals without providing detailed information and thereby leading the decision about psychiatric medication. As discussed above (S. 9.2.2.1) some psychiatrists refer to holding back information in certain circumstances. Psychiatrists acknowledge that certain side effects, such as sexual side effects or other 'longer term' side effects are not discussed as frequently. In addition when someone is deemed to lack insight arguments are constructed and information presented so as to avoid conflict and encourage adherence.

⁷⁹ a term taken from the work of Habermas (1987)

Taken together, the findings link well with Lukes' second face of power. This focuses on the acknowledgement that what information is available to discuss in the first place is an important consideration in how structural power is enacted in medication management practice in a community based setting (Lukes, 2005)⁸⁰. As mentioned previously, overt forms of power, 'power over' or coercion were not observed in the findings, instead having found support the ideals of service users having increased say and control over decisions concerning psychiatric medication.

That is not to say that structural barriers at the system level, which result in overt demonstrations of power in medication management practice more generally, do not exist. Indeed, service users and psychiatrists in these findings both mention the importance of a general 'fear of coercion' which hinders an open and honest dialogue. A person's previous experiences of coercive practice and of being treated against their will under Mental Health Act legislation, was noted as having a particularly damaging impact on the formation of a collaborative relationship with practitioners. This supports previous research illustrating the negative impact a fear of coercion has on achieving SDM, instead encouraging greater passivity, 'false compliance' and a lack of engagement with mental health services (Chamberlin, 2005; Campbell and Schraiber, 1989; Haglund et al, 2003). However and interestingly, this theme emerged even amongst those service user participants who had not had any personal prior experience of direct coercive treatment, indicating a more insidious form of structural power present in the medication management encounter. Thus, an underlying awareness of coercive aspects of the mental health system appears to hinder a fully collaborative approach. Boyle (1993) refers to the need to emphasise *both* the juridical aspects of power in the mental health system, alongside structural theories such as Foucault's 'disciplinary power'. Boyle (1993) suggests mental health legislation has a dual aspect, both to sanction the enforcement of treatment against a person's will, but also acts as a form of disciplinary power *in constructing and producing and in using language for subtle forms of self and social regulation* (ibid; p 71). Mental health legislation relies on scientific expertise from mental health practitioners, practitioners, GPs and the Approved Mental Health Practitioner (AHMP) and this may thereby further more insidious forms of disciplinary power.

Interestingly, unlike psychiatrists, CPNs did not note the trend that fear of coercion was important for decision making in the CMHT. Perhaps this is more suggestive of the

⁸⁰ See chapter three for further details

differing role CPNs are seen to perform in the medication management process, conceptualising themselves as a 'helping profession' emphasising caring aspects of their role, as oppose to components on managing risk and control (see S. 9.3.2).

9.4.2. A third face of power

Another key finding from the interviews is that, whilst some service users found receiving a diagnosis helpful, more often they refer to feeling labelled, stigmatised and feeling pre judged as important barriers to being involved in decisions about psychiatric medication. The acceptance of a mental illness diagnosis can be stigmatising and potentially lead to loss of control. Diagnosis may strengthen stereotypes associated with mental illness labels, intensifying the depersonalisation and otherness associated with public perceptions of mental illness (Corrigan, 2007). Stigma comes not only from family and society generally, but also via the process of the person internalising it (Brohan et al, 2010; West et al, 2011), as well as the knowledge that a diagnosis may interfere with life goals, job prospects and social opportunities more generally. In addition, stigma is associated with label avoidance, where people avoid treatment and services associated with a diagnosis (Corrigan, 2007). Other recent research outside of mental health has found that fear of being labelled is a key challenge for shared decision making (Frosch et al, 2012). Taken together, the findings suggest that labelling is a particular challenge for collaborative psychiatric medication management practice.

Thus, in addition to a second face of power, a more insidious form of power (or a third dimension) is also observed in this data. Foucault's writings and more contemporary research which has explored the ideas of clinical gaze, self examination and control in modern mental health systems, combining normative judgements and self governance, is relevant here, along with notions of positive power (Foucault, 1977; Terkelsen, 2009; Rose, 1998).

9.4.2.1. *Lacking insight - devaluing experiential knowledge*

The findings discussed previously in section 9.2.2.5, are of particular relevance at this point. For professionals, lacking insight into one's condition is an important barrier, which contrasts with the findings from service users. By 'insight' practitioners mean accepting having a mental illness and the necessity to be treated. The emphasis on acceptance of having a diagnosis or acceptance of illness is seen as important for recovery. Yet, the data from service users emphasises problems of feeling labelled in terms of reflecting stigma

and loss of control. This fits with research which suggest that service users who accept illness labels as applicable, may gradually begin to view themselves as incompetent (Estroff, 1993) by association of accepting stigmatising beliefs about mental illness (Lysaker, Roe and Yanos, 2007). The findings also point to a pivotal barrier at the system level for achieving a 'meeting of experts'; the capacity to reason and make effective decisions. This may also be applicable to other areas of medicine. However, while in other areas of health, capacity may be limited by service users' knowledge of medical conditions and treatments, their ability to reason is not in dispute. In mental health, the capacity to reason and make effective decisions is in the hands of others rather than by the person themselves. Part of this is defined in legislation and part through the social construction of professional practice unique to mental health (Morant, 2006). For example, in Wei Wen Chong et al's (2013) study (see S. 9.2.2.5), only mental health practitioners prioritised 'SU lack of competence' as a particular challenge for shared decision making, a factor not considered by practitioners in other medical contexts. As such, a key challenge for shared decision making in psychiatric medication management is that practitioners (at times, at least) do not place equal value on service user expertise and knowledge⁸¹. Yet, for shared decision making to become a reality, experiential understanding as well as an acknowledgement that conceptions of mental illness and treatment are contested and complex, need to be at the forefront of conversations. According to Baker et al (2013) there needs to be a:

...rebalancing of the traditional focus on diagnosis and treatment with prioritisation on personal and self determined perspectives. A key component of this shift would be the value and status that is ascribed to different forms of knowledge.

(ibid, p. 3)

The rejection of the value of experiential knowledge is related to the belief that, given the subjective nature of such knowledge, it is inferior in its validity to that of medical knowledge, which attempts to be based on scientific or objective knowledge. These findings suggest that such challenges still remain, and this is highlighted by practitioners' emphasis on the importance of insight, without which, the service user perspective is ignored and devalued, thereby continuing negative cycles of resistance via non adherence as a positive attempt to regain control (Britten, 2010; Roe, 2009).

⁸¹ Either 'raw' individual experiential knowledge or 'collective' forms of knowledge (See Borkman, 1999)

Generalised structural barriers, non specific to mental health, also appeared in the data. Asymmetry of the encounter and power associated with the role of the psychiatrist as an expert and a doctor, with higher social status, was seen to preventing open dialogue. Service users refer to feeling spoken down to and 'feeling like a child'.

9.4.2.2. Diagnosis and the dominance of the bio medical model

Psychiatrists and CPNs also refer to more insidious forms of power being present in the encounter, this hindering honest and open dialogue about psychiatric medication. However the content of this discussion differed from service user perspectives. Practitioners refer to particular trends of an increasing medicalisation of emotions and behaviours and increasing societal expectations for prescribing, as particular challenges in medication management practice. For some psychiatrists (e.g. see Dr White, S. 6.2.3), this was linked with the suggestion that, in a minority of meetings the service user puts pressure on the psychiatrist to fix or offer a quick solution to their problems and that this, in of itself, is a barrier to involving people in decisions. Both these findings, alongside the service user interview findings, of feeling labelled and diagnosis as a depersonalising process, support the concerns that have been raised about increased medicalisation of distress and behaviour (Conrad, 2007; BPS, 2011). This supports literature in medical sociology describing contemporary concern of the growing power of medical expertise in everyday life leading to an increasing depersonalisation of experience and creation of the 'sick role' identity; lacking agency and control (Scrambler, 2012; Estroff, 1989).

In trying to answer why there is reference to people feeling 'unable to act' or psychiatrists feeling certain people placing pressure to prescribe, it is possible to interpret this data with the fatalistic view that the structural factors of the mental health system offers the *potential [for mental health service users] to be constructed as the other* (Estroff, 1989) which is partially observed in this data (see fractured passivity typology, S. 9.2.2.2). This may present a form of learned helplessness and an inability to act, ultimately creating passive recipients. This position is in line with sociologists, such as Foucault and Bourdieu, who emphasise the more insidious forms of self regulatory power via wider knowledge production processes. Such a perspective is described eloquently by the psychiatrist and critic, Thomas Szasz (1922-2012) :

the demoralisation and de politicalisation of social problems and transformation into problems of medicine and treatment, ...The essential aim is always the same: to identify, to stigmatize and control particular segments of the population.

(Szasz, 1997, p.207)

The recent controversy in the mainstream press surrounding the expansion of the newly released DSM-5 is a good illustration of this point. Alongside its recent release in 2013, there have been a growing and diverse body of concerns and criticisms published. For example, the addition of a new syndromes such as 'disruptive mood dysregulation disorder' (which historically has been conceptualised as a normal developmental expression of behaviour in young children, known in lay terms as 'temper tantrums'), has caused widespread controversy (DCP, 2013; The Economist, 2013). In addition, there are growing doubts as to validity and reliability of heterogeneous diagnoses such as depression and schizophrenia and general concerns over the dominance of a disease model as a basis for classification (DCP, 2013; Pilgrim, 2007). According to the Economist (2013) *in the eyes of many critics the DSM is a vehicle for misdiagnosis, over diagnosis, the medicalisation of normal behaviour and the prescription of a large number of unnecessary drugs*. Finally, this latest, and more expansive, version of the DSM continues to ignore the recovery approach (Zizman-Ilani et al, 2013).

Shared decision making does not occur in a vacuum, but is a central tool in enabling service users to take action and exert agency and control in the mental health system. However, much of the SDM literature ignores the structural and system level constraints that SDM sits within. Some of these structural factors are applicable across many medical contexts (for example, asymmetry and dominance of Cartesian knowledge in the medical encounter) and others are more directly applicable and specific to the mental health context (e.g. judgement of insight, capacity, fear of coercion and diagnosis, labelling and stigma). These structural barriers present particular challenges of different forms of knowledge having equality in psychiatric medication management practice. In other words all of these structural factors maintain the influence and perception that medical expertise remains considerably more valued than experiential knowledge, thereby hindering open and shared dialogue in the psychiatric medication management encounter. By ignoring these structural factors, the terms shared decision making may be criticised as unachievable, idealistic and purely fictitious rhetoric (Wirtz 2006; Quill and Brody, 1996). A similar criticism can be made of the recovery agenda, which pursues the concept that the individual has control and agency over their lives, with hope and opportunity for the future, without really making explicit the structural factors which exist and hugely influence this (Shepherd and Boardman, 2009; Roberts and Hollins, 2007).

Having said this, it should be acknowledged that the historical roots of the recovery agenda emerge from a growing awareness and movement against oppressive structures in

the mental health system, so in of itself the recovery approach has been seen very much as a critical perspective on traditional practice. Indeed many interventions inspired by the recovery movement, now both acknowledge and have the aim of increasing service user input and participation by making explicit the imbalances in power and promoting greater service user control⁸². It would appear that promoting the importance of a respectful culture which recognises service user expertise and communicates belief in individual potential is particularly important for promoting shared decision making for psychiatric medication management, as has been evidenced in previous research (Baker et al, 2013; Davidson et al, 2008; Shepherd, Boardman and Burns, 2010; Shepherd, Boardman, and Slade 2008; Bird et al, 2011; Tondora et al, 2005; Shera and Ramon, 2013; Fitch et al, 2008; Tees et al 2007; Quill and Brody, 1996; Edwards and Elwyn, 2006).

In summary, the findings point to an underlying culture and structure of power present in the system. In particular the emergent themes suggest that the largely unquestioned domination of the bio medical model is problematic for shared decisions. The structural constraints of categorising and labelling based on descriptions of experience and behaviour and associated with the assumptions of specific and underlying biological makeup continues to be prevalent in mental health services. This is a hidden and more insidious form of power, hindering a shared dialogue in medication management practice and pushing experiential knowledge to the periphery of the decision making process.

9.4.3. A complex structural system and the role of agency?

However, but importantly, the findings from this thesis also emphasise diversity in levels of service user participation. There was also wide spread support for giving the service user increased control and agency in decision making for psychiatric medication management. However, many contradictions emerged. There is a need to explain and theorise about the possible reasons for such a wide spectrum of response and the juxtaposed discourses seen in the data. I propose this diversity suggests a far more multifaceted and complex picture of the interaction between structure and agency, than offered by structural theorists, such as Foucault.

Today, perhaps more than at any other point, there are multiple perspectives and discourses present in mental health services resulting in multiple dialogues about the causes and treatment in mental health. While as discussed above, there is a continued

⁸² See chapter one for further discussion of the recovery movement

dominance of a medicalised approach in mental health services, there is nevertheless widespread discourse and acknowledgement of social and psychological models. The stress vulnerability model (presented in chapter three), alongside the bio-psycho-social model is widely cited and part of main stream discourse in mental health services (Zubin and Spring, 1977). Wider trends in recent decades are also of note, such as the growth in neo liberalist ideals, resulting in an agenda of increased choice and competition in how services are delivered within mental health and beyond (Terkelsen, 2009). This is particularly poignant to ongoing mental health service delivery changes towards increased competition and the enforcement of the 'purchaser - provider' split, apparent in the recent Health and Social Care Act, 2012. Neo liberal roots also link to the individualist nature of service delivery in healthcare, with broader collective approaches to knowledge and expertise very much at the periphery.

Even within the 'psychiatric model' more than one discourse emerges. For instance, on the one hand, there is a growing public interest and research exploring the biological (and in particular the genetic) markers to behavioural outcomes. Advocates propose that development of knowledge in this area will assist diagnosis and treatment. According to this discourse, there is hope that future disease classifications may be based on neuroscience as oppose to the current phenomenological approach to diagnostic categories such as depression or schizophrenia. Most notably the National Institute of Mental Health has launched the Research Domain Criteria (RDoC) initiative with just such an aim (Cuthbert, 2010; Fibiger, 2012). On the other hand, in a recent mainstream newspaper article, a diametrically opposed position is portrayed (Bell, Guardian, 7th April, 2013). Here recent research was conferred that found the same genetic risk factors were applicable across diverse psychological and behavioural outcomes, concluding that the likely outcome of these particular genetic factors are mostly a result of our life experiences (Tandon et al, 2013). The author concludes: *'thereby to regard [depression, schizophrenia and other diagnoses] as a discreet disorder, or set of disorders within specific causes, symptoms and consequences is no longer tenable'*. Possibly more interestingly, however, the article reflects that the fact that these findings are in the wider media, in itself, represents that psychiatry is entering a mature era, where *'from diagnostic shortcomings we are recognising the need to treat patients as individuals'* (Bell, 2013). Indeed, the recovery discourse links in here and its refocus on the individual and the provision of hope, opportunity and choice (see context chapter). For medication management, while not objecting to psychiatric medication as one possible treatment strategy within a range of interventions, recovery discourse is concerned with the frequent and lasting adverse

effects of such medication (Pilgrim, Rogers and Gabe, 2011; Whittaker, 2010), the lack of choice by service users, the lack of consideration of experiential knowledge, and the search for a much wider range of intervention options. These perspectives are also mainstream and form part of the wider discourse within mental health medication management.

The recovery model is not the only discourse which has emerged from social resistance movements in psychiatry. Where structures associated with medicalisation and psychiatry exist, there is also a history of resistance and of new movements. For example, Crossley's (2006) sociological examination, presented in the theory chapter, recognised five distinct, but inter related social movements over the period of 1950 - 2000, concluding these structures have sometimes been in conflict, but are ultimately connected, these connections defining their identity. He concludes that these 'fields of contention' are highly complex spaces.

Thus, the picture that emerges is the need to explore the individual in a complex multifaceted and dynamic system, where high uncertainty exists and where continual change and interaction between structures is present. The findings of this study fit with the dualist perspectives of Archer and Giddens, with features of a late modernist society including flexible and overlapping structures, being emphasised (Giddens, 1984; Archer, 1995)⁸³. Thereby to understand and conceptualise what is possible for involving people in decisions about psychiatric medication, the concept of agency in the context of this multifaceted system is central.

The conceptual framework adopted for this thesis took the middling position that both structure and agency are present and influence the sharing of decisions in psychiatric medication management.

A widely cited definition of agency is:

'agency as power which ultimately enables them to reflect upon their social context and to act reflexively towards it, either individually or collectively'

(Archer, 2000, p. 308)

The data from interviews and the recorded meetings broadly fits with this, while showing that there are different modes of agency being enacted upon. The diversity of findings I suggest supports the idea of a *system of explanation* (represented as a typology in table 10)

⁸³ See theory chapter for further discussion

as an analytical attempt to disclose individual agency as well as cultural and social influences of involvement in decisions about psychiatric medication (Larsen, 2004). These modes of explanation are in continual flux and negotiation and different modes may be pulled upon in a person's recovery journey, but also in the system they find themselves in. Following Archer's (2012) analysis of the four modes of agency (see theory chapter), the diversity in participation in these findings may, in part, be explained by difference in modes of agency and the idea that people draw on different modes at different times and are in constant negotiation. People may move from fractured passivity, through to active self management as part of this iterative process.

I suggest then that the findings from this thesis point towards the need to incorporate a multifaceted, complex structural discourse and explore how agency operates in this context. Archer's model is useful to consider as it allows for an increased appreciation of a flexibility towards structural components of the mental health system, and for the diverse combination of different vested interests to be more explicit in understanding how people enact their agency. Whilst dominating structures are present (e.g. fear of coercion, diagnostic categories, labelling and medicalisation) and pose a challenge to SDM in psychiatric medication management, there is also opportunity and acknowledgement of a continual and changing environment. In the intersections between diverse structural components of the system, the individual has the opportunity to process this dynamic environment and reflect upon it, thereby encouraging further change, as illustrated in the quote below.

As individuals and groups are acting in situations to defend their vested interests and to realize their projects, they reproduce or transform the structural and cultural conditions that impinge on them, but in this process they are themselves being transformed from involuntarily placed agents into social actors and individual persons.

(Archer, 2012, p. 31)

In summary, unlike the overly fatalistic stance of people's actions being a consequence of the dominating structural components of the system, I think the findings also offer a positive and dynamic perspective on agency. However, within a multi faceted structure, there is continual flux with different modes of agency being drawn upon. This does also present a worrying perspective; the suggestion that the proportion of fractured reflexives may increase.

On a related point, this uncertainty, and opportunity associated with late modernity in sociology, has also been proposed to be related to a growth in health inequalities, suggestive again, that this high uncertainty but dynamic structural setting of mental health may not suit all (Scrambler, 2012). This may be a significant challenge for shared decision making in medication management. Yet, this structural complexity and uncertainty also offers increased opportunity for service users⁸⁴ to enact their agency, and further impact structural and cultural components of the system.

9.5. Conclusion

This chapter has presented and discussed the findings, relating back to relevant theory and literature to build an original, rich, and contextualised understanding of shared decision making for psychiatric medication management. Three levels of analysis (the interaction; the relationship; the system) have been used to provide a coherent structure from which to base the discussion. The focus throughout has been to explore the complexity and divergent aspects of the findings, and its multidisciplinary background, alongside learning from the experiential knowledge of service users. It is through the exploration of this complexity, that a fuller, contextualised appreciation of medication management practice is presented.

⁸⁴ Collectively and individually

Chapter Ten. Conclusion

Chapter outline

This chapter concludes the thesis. Implications of findings are discussed, and original theoretical and methodological contributions to knowledge are presented. This is followed by consideration of limitations of the study and suggestions for further research.

10.1 Introduction

This thesis has explored the views and experiences of both service users and practitioners to build a comprehensive understanding of the everyday realities of psychiatric medication management in a community based mental health team. Barriers to and enablers of SDM for psychiatric medication have been investigated, building a sophisticated, multi-faceted construction of shared decision making for psychiatric medication management.

The study has adopted a social constructionist research framework, with a strong focus on participatory values. This, in addition to the incorporation of different stakeholder group perspectives, has allowed for a rich understanding of the key concepts to emerge. There were two phases to the data collection process - a research interview and digitally recorded meeting. A qualitative approach to data collection and data analytical methods was employed.

10.2. Implications of findings for policy and practice

Findings show SDM to be a highly dynamic and protracted process. Therefore any intervention to encourage greater SDM in practice would need to incorporate a multifaceted perspective, involving both the practitioner and service user at a number of different but interrelated levels. At the micro interactional level, the study highlights the gap between ethical ideals and actual practice. Future interventions could therefore be employed to target these specific gaps. For example, the lack of a detailed weighing up of psychiatric medication side effects was observed across the data sets and themes from stakeholder group interviews. A key challenge for SDM is how service users are to best access full and balanced information concerning psychiatric medication and be supported

to take control over the process, making an informed choice. It may be that 'patient focused quality interventions' would benefit practice (Coulter and Ellins, 2007). Tools to improve health literacy (e.g. leaflets and provision of internet based medicine information) alongside decision aids may help service users process and direct these complex decisions. However these findings also point to the importance of discussion and dialogue in helping service users feel more informed. Therefore tools with a particular focus on improving dialogue and open communication as part of existing interactions are strongly implicated by these findings. Coaching sessions before and after formal consultation meetings may increase a person's confidence and skills in the preparation and deliberation process (O Connor, Stacey and Legare, 2008). Techniques such as motivational interviewing have proven effective and may be useful to consider (O Connor, Stacey and Legare, 2008).

Increased support and training for health professionals in person centred communication and recovery oriented prescribing is also indicated in the findings. An example of such work currently underway is the ShiMMe project (see Chapter one). The roll out of Recovery Colleges as part of the ImROC program may also improve training skills building and awareness in this area, alongside the potential for peer support workers to undertake coaching duties affecting outcomes at all levels of analysis.

Service users acknowledge and value more guidance in times of crisis, and strongly believe that SDM can only happen in the context of walking a journey together in a trusting, supportive and honest long-term relationship with a practitioner. These results support broader conceptualisations of shared decision making, emphasising a protracted process, but in the context of an established trusting relationship. In short, the therapeutic relationship was seen to enable increased service user involvement in decisions about psychiatric medication. Policy makers and practitioners could look to further emphasise the importance of therapeutic relationships for shared decision making, promoting increased reflection, awareness, support and training for all mental health practitioners. In particular, the practitioner's role in supporting recovery and self determination may be an important avenue for future mental health policy and practice (Markwick, 2013; Farelly and Lester, 2014). In addition, promoting continuity of care in policy and practice may be an important implication of the findings (NICE, 2014).

Finally interventions to encourage greater shared decision making in reality need to tackle structural and cultural components of the system. Overall, the findings point towards a

multifaceted complex cultural system which impact on how individuals are able to enact their agency. This thesis suggests that it is important to accept and acknowledge this complexity in the system, encouraging a more democratic and positive risk-taking culture with a priority on honest and shared dialogue between service users and practitioners. For psychiatric medication management, the continued dominance of an overly medicalised approach is a threat to a meeting of experts and of experiential knowledge holding weight in medication management encounters. Perhaps the consistency of CPNs positioning themselves more alongside service users suggests broadening in the types of knowledge within the system. The recent introduction of peer workers in mainstream UK mental health services may also serve to bolster the value of lived experience in knowledge production processes in the mental health system. The fact that both practitioners and service users expressed and reflected upon some of these system level barriers in this research is, in of itself, suggestive of change occurring. In addition there is a need to increase opportunities for engagement of collectives of service users in the system, and to move beyond individualistic solutions.

10.3. The original research contributions

10.3.1. Theoretical contributions

This thesis makes significant theoretical contributions to the conceptual development of shared decision making for psychiatric medication management.

It highlights the structural components and dynamic nature of SDM, often ignored by SDM theorists. It brings to the fore a consideration of some of the insidious components of the modern mental health system and incorporates the concept of power - a factor central, yet often ignored when discussing SDM models and concepts. By including an appreciation of terms such as second and third face of power in discussion of how SDM occurs in reality, a significant contribution to conceptual development of SDM is offered (Lukes, 2005). This thesis also includes the important concepts of structure and agency in the psychiatric medication management encounter, showing how opportunities for increased agency exist in a complex multifaceted system, yet may at times result in modes of fractured passivity (Archer, 2012). By exploring the concepts of structure and agency, future models of SDM may incorporate a more dynamic and less static perspective.

Thus, broader conceptions of SDM are supported and added to by the findings from this thesis. SDM is proposed to be a longer term process of trial and error, prioritising honest open dialogue, experiential knowledge, and the consideration of psychiatric medication as

only one possible choice in a wider personal tool box approach (Davidson et al, 2008a; Entwistle and Watt, 2006; Deegan, 2005;2007).

This thesis also highlights the enabling role strong therapeutic relationships (TR) play, for SDM to become a reality in community based mental health services. Whilst TRs have historically been linked to many positive outcomes in mental health, its connection to shared decision making has been relatively unexplored. This thesis supports research which suggests that positive outcomes of TRs may be mediated by its impact on increased involvement and shared decision making (Street, 2009; Stanhope; 2013). As such, this thesis supports a broader and more person centred conceptualisation of SDM for psychiatric medication management.

10.3.2 Methodological Contributions

The exploratory nature of this study has enabled a rich and contextualised picture of collaborative psychiatric medication to emerge. The methodological choices and incorporation of different stakeholder groups have allowed the findings to be grounded in the experiences of both people receiving mental health services, and mental health practitioners.

The combination of data collection and analytical methods used has also enabled fresh insight to be gained in this topic. Two phases, with different analytical methods were merged to multiplicatively enhance the findings. In particular the use of the recorded meetings data to supplement information from interviews is a key strength of the research design adopted. More than merely adopting a triangulation approach to enhance authenticity, this combination of methods has also allowed for an in depth exploration of the research topic, by exploring both what research participants value and prioritise as important, based on their previous experiences (phase one interviews), alongside an exploration of how participants are involved in decisions about psychiatric medication in practice (phase two). As part of this analysis, discrepancies and areas of convergence between the interview and the recorded meeting data was explored for individual participants in a case study style of presentation, enabling a far more in depth understanding of the research topic, than just an addition of two separate data collection methods.

Whilst participatory methodology is not in of itself new or innovative, the detail and planning which has gone into the participatory components of this study offers

contributions to participatory methodologies. Firstly, how were the goals of a contribution to knowledge, required for a PhD thesis, combined with the more emancipatory roots of participatory research? While this was not a full scale PAR study, in that change and action was not a primary goal, nevertheless the involvement of service users, a carer, a CPN and a psychiatrist, in the full life cycle of this project (including the planning, training, conducting interviews, analysis and dissemination phases) has ultimately had profound implications on what this research did, both indirectly through encouraging my own personal reflection on the topic, and directly through guidance and input at each point in the research life cycle. Of particular note is the collaborative analysis phase to the project, which has not been widely adopted in a PhD research context. The detail of this aspect of the research process adds understanding and credence to how the collective analysis process is able to enhance the meaning and interpretation of data, both through enhancing validity, and ensuring the voice of people who have direct knowledge and experience of a sensitive topic, such as this one, is maintained in the context of PhD research. Some of the challenges and opportunities that emerged from the collaborative analysis, and the impact this had on the findings is an important contribution methodologically. See the methodology chapter, S. 4.4.1, and appendix VII for further details.

Secondly, being the sole researcher and facilitator for the project required sensitivity and reflection to ensure the participatory components of the project would be fruitful. Structured facilitation skills were particularly valuable in the earlier phases on the project, but also emerged as important later in the analysis phases, where differences in the interpretation of transcripts emerged between group members. The group dynamics between service user members and the practitioner member were more strained during these phases of the project, and required more structured facilitation; to acknowledge conflict, build consensus, or where this was not possible, respect difference. In addition it was a tricky balance to ensure that my interpretations and pre existing knowledge did not dominate the collective analysis process. Recording and transcribing collaborative analysis meetings were particularly beneficial in this regard (see appendix VII for an example of a meeting (transcribed) during the collaborative analysis).

Lastly but perhaps most importantly, is the impact the participatory components of the research had on me personally and on other members of the group. By building relationships with both service users and practitioners working in mental health, not only has my knowledge and appreciation of mental health and illness grown, but also my views

and values towards research in applied contexts more generally, have changed. I have changed from viewing research in abstract terms: as an objective, neutral observer building knowledge and theory on a topic, to an interested and passionate participant in research: the idea that research in of itself is a way of engaging with social nature of reality and promoting change and positive reflections on it.

The research process has also had positive impacts on other members of the group. This was poignantly illustrated in a response given by one co researcher at a recent presentation. One co researcher (new to research at the onset of this study), was asked by an audience member at a recent presentation in July 2013, *how has being involved in this project impacted you?* The notes I took of his response were: *In short it has changed my identity. I will explain what I mean. My mind set has changed. At the start of the study, I still had a CPN myself. Through being involved in this study, I started to see my CPN differently - as a person - and they started to see me as a person. And consequently, I no longer have a CPN...*

These reflections on personal change and identity as a consequence of the participatory nature of this study, offer significant methodological contributions to participatory focused research.

10.3. Limitations

As with any small scale qualitative study, far reaching conclusions are not possible from observations of a handful of selected meetings, or from a small sample of interviews. However, this was not an intention or goal of this research, and the exploratory nature of the study is not seen as a limitation. Yet it is acknowledged that the original plan was to recruit greater numbers of both: service users for phase one interviews (n=30) and, recorded meetings for phase two (n=10).⁸⁵ Additionally, the scope for an additional 'reflection and action' phase was reduced following recruitment difficulties⁸⁶. The original plan included a third phase of three discussion groups, with service users and practitioners, discussing preliminary findings and encouraging reflection about current practice. This phase was scaled back - only one feedback and discussion group (conducted with practitioners from the CMHT) was undertaken.

⁸⁵ To note, practitioner interview numbers were satisfactory and as expected. Indeed in both cases, all but one of the psychiatrists and CPNs from within the team, were interviewed.

⁸⁶ The possible reasons for the recruitment challenges are discussed below.

It is also important to highlight that the population from which this study recruited is not representative of the wider UK context. The majority of the sampling took place in an affluent city with far higher than average education levels present in the general population, due to the presence of two universities. The region also has lower percentage of BME residents and is expanding as a commercial centre rapidly, again not representative of much of the rest of the UK. It is likely that these factors had a significant impact on the findings of the study and further research would benefit from being located in other, more representative, areas.

The local context also had an indirect impact of the recruitment challenges experienced in this study. In addition to two universities, the city hosts a regional research hub and teaching hospital. The regional mental health research network hub (MHRN, part of the NIHR⁸⁷), boasts by far the largest number of supported research projects, as compared to the rest of the UK. This study, on the other hand, was a small scale unfunded PhD, without wider support than that of a supervisory team. This was a likely reason for some of the recruitment challenges experienced in this study. The use of gatekeepers for recruitment of service users to the study was also particularly problematic. Most clinicians and care coordinators approached were already involved in multiple research projects, therefore impacting on the 'buy in' to the project, and subsequently impeding recruitment. Although various strategies were incorporated to promote relationships with clinicians in the team including; presentations and attending team meetings; regular contact via email and phone calls; and escalation meetings with senior clinicians and management, a research fatigue did nevertheless appear to hinder the recruitment of service user participants. Even when gatekeepers directly offered support for recruitment, this often did not result in the actual invitations being sent out to service users. Administration problems and changing priorities for the clinicians were a common issue. Additionally, at the time of the study, mental health services (locally and nationally) were undergoing significant organisational uncertainty and change, with increasing pressures on staff. This is likely to have affected both recruitment and the findings.

In addition and more generally, the recruitment design itself has limitations and introduces bias into this study. It is possible that those practitioners with a particular interest in this study were more amenable to assisting in the recruitment of service users to the study, thereby influencing the overall sample of the service user participant group.

⁸⁷ National Institute for Health Research

This may have subsequently impacted recruitment to phase two. As mentioned above, it was in fact only possible to record four separate meetings (out of an intended 10), and all four took place with the same psychiatrist. The question then arises as to why did only one psychiatrist participate in this phase of the study (out of a possible total of seven)? Recruitment of psychiatrists to this phase was only successful indirectly, via service users who partook in interviews (phase one) inviting their practitioner to the recorded meeting phase. On the surface at least, I would have expected that different psychiatrists (or indeed other practitioners in general) would have, in all probability, been invited to this phase of the data collection. However, this doesn't take into account the support that this psychiatrist may have given in the initial recruitment of service users to phase one interviews. It may, of course, also be the case that this psychiatrist was in some way more approachable than others, thereby offering us a distortedly positive picture of these interactions at the micro level.

A final consideration is the limitation of the design only taking place at one point in time. In particular, findings could have been enhanced greatly by introducing a longitudinal component to the design – exploring how decision making occurs in the context of developing/not developing relationships and a person's individual recovery journey.

10.4. Suggested future research

Future research in this area may look to focus on other treatment settings and localities, enhancing the ability to generalise findings and explore different contexts for SDM in the UK mental health system, and beyond. Recent progress in the NHS research IT database systems would also assist in overcoming some of the recruitment challenges experienced in this research. In particular the ongoing development of the care register interactive search database (D-CRIS) would enable direct access to potential participants, therefore potentially bypassing the challenges of a reliance on gatekeepers in the recruitment process (CPFT, 2013).

The findings have highlighted the usefulness of participatory research. Hence there is scope for further research in this area to adopt participatory methodologies to explore action and change components, encouraging reflection and change locally. In PAR based research projects, understanding between different stakeholder groups is increased thereby encouraging change and positive risk taking. Initiatives in the UK include: in Devon the recovery oriented prescribing group (e.g. see Baker et al, 2013), and in

Northumbria, the PAR study exploring recovery oriented care coordination (Brandon et al, 2013). The national organisational program, ImROC⁸⁸ is also of note, promoting a wider cultural change in the mental health system. However there is scope for the research components of ImROC to be expanded further, exploring its impact upon SDM outcomes such as the value of experiential knowledge for clinicians, and the empowerment and confidence of service users in decision making interactions.

As mentioned above, SDM is found in this study to be a long term process occurring as part of ongoing developing relationships. It would therefore be very important for future research to incorporate a longitudinal design, to explore how SDM occurs as part of recovery journeys. Choice and control are fundamental concepts for recovery, and therefore further research which examines shared decision making, in the wider context of recovery would be valuable. In particular, therapeutic relationships and their impact on how people with serious mental health problems are able to take back control and exert agency is an important avenue for future research. More research is needed which is focused on exploring the links between these factors. By increasing understanding of the mechanisms through which choice is best utilised in the achievement of recovery outcomes, there are significant opportunities to benefit mental health services. The central issue of roles and accountability with mental health teams also needs to be included in these investigations. For example, there may be increased role for other members of the mental health team, including peer support workers to offer the support and advocacy during more difficult times. In addition, the wider changes and the increased responsibility for the GP in day to day contact service users experience, alongside growing financial pressures, present questions as to how these changes will actually translate to people's experience? (Coulter and Collins, 2012; Patterson, 2012). This is an avenue for further research to explore.

Research could also explore the impact of coaching on mental health outcomes more generally, and more specifically on SDM outcomes. This would be an exciting avenue with many implications for practice. A particular focus on whether specific roles or groups performing coaching duties, impact on these outcomes, would be an interesting question to explore. For example, whether STR workers (Support Time and Recovery) and peer support workers offer a qualitatively different or enhanced experience, as compared to other members of the multi-disciplinary team.

⁸⁸ See chapter one for further details

10.6 Summary

This chapter concludes the thesis with a presentation of the key implications emergent from the thesis, providing suggestions for future research. Contributions to both theory and methodology are highlighted, and limitations of the study acknowledged.

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Appendix I. Example minutes taken from an advisory group meeting

4th Meeting

Minutes

Date: 25th January 2011

Attendees

(DH)

(EK)

(GS)

(JS)

(MM)

(SR)

(FI)

- Project update and feedback
 - NHS ethics application update (EK). Full approval given by ethics committee. Only minor amendments to supporting documents were necessary following committee hearing.
 - RandD approval outstanding
 - Co researcher governance checks. Co researchers may also need research passports within the NHS trust. **Action** EK investigating other possibilities for this.
 - Need to introduce project to practitioners within ITT by meeting with psychiatrists and CPN team leaders in addition to attending team meeting to introduce project. **Action:** FI and DH will approach colleagues in the pathway to assist with access.

- Interview Schedule

Critical incident questions explored and role plays conducted within group to explore the content of this section of the interview and suggestions for improvement.

Feedback from interviewers included:

- Difficultly to always follow the questions: didn't want to keep looking down at sheet.
- The bullet points in the schedule (topic areas to explore) were not easy to understand
- Hard to focus on the positive and negative examples separately. 3rd question 'a time that sticks in the mind' easier to work with.
- With practitioner questions, maybe need to be more specific. For example, instead of 'what did you want to achieve at the meeting' you could ask, name 3 things wanted to achieve at the meeting
- It may also be useful to explore in more detail, who the meeting was with that is being talked about
- Maybe difficult to pull out one meeting or situation as a decision: to review.

Feedback from interviewees included:

- Felt good to answer questions and talk on this topic. Nice experience.
- Interviewer made me feel relaxed and comfortable and I really enjoyed the interview because of that.
- Difficulties with remembering specific meetings and details. Couldn't remember specific meeting easily but instead more general memories about meetings.
- In practitioner interview, would have preferred to start with a positive example and not a negative question.
- Questions were too open ended. Needed to be more specific.
- In practitioner meetings, generally didn't think of one example but a few different examples that helped to illustrate the point.

Additional thoughts and suggestions from group:

- To help with talking about specific event instead of thinking in general, need to dramatise the questions emphasising the positive and negative. Eg Can you think of a meeting which was a 'complete disaster' or 'really productive'. Or maybe use terms such as one of the best or one of the worst.
- During the training it will be important to ensure that all researchers feel comfortable in asking the questions if they are worded in a more dramatic way.
- Going back and reviewing the research questions will help answer the question as to how specific to one event or how general to keep the questioning

- In the practitioner schedule it may be useful to replace the term 'consultation' with 'a meeting with a service user'
- The time period to use when thinking about a certain memory or event should be longer – 12 months.
- The time period should be referred to throughout most of the questions, to keep reminding people to try to think about the last year only and should also be referred to at the beginning of the interview.
- Support for co researchers. Being able to have a chat following each interview. Need to build in an informal debriefing for researchers within the research group following each interview. To be planned in advance when organising interview timings.

Actions

EK to review above reflections and amend interview schedule and plans accordingly.

EK to send amended schedules to team for further review via email.

AOB: None

- **Proposed next meeting date: Tues 29th March 2011 4-6pm, ARU. Please confirm attendance asap.**

Appendix II. Selected entries from the research diary

General reflections, group dynamics and data collection preparation including co researcher training

May 2011

Training and co researchers: two training sessions have been undertaken. Far more time is needed than I originally thought and we are still not near being ready to go (that includes me – I feel more preparation is necessary). SE SURG provided a good introduction and this session helped building confidence within the group, in research skills.

The co researcher group is strong and there is a good mix with different skills apparent. After the first training session, I was worried there was too much variation in style in conducting the interviews, and some group members have a strong preference to go off script. What should I do about this? My initial reaction was to create more structure in the interview schedules, and encourage the use of the script, learning questions before the interview. I facilitated the second training session, and used this approach. I was impressed with the interviewing skills of the group. Again individual style varied and not everyone felt the need follow the script. This may be just due to it being a supportive and training environment and not the 'real' thing.

June 2011.

Busy period - I had another (3rd) training session on Friday with co researchers in addition to a steering group meeting. It is a very confident group now. It was a rather a tricky start to the session, dominated by a lot of commenting on the script, whereas the main purpose was to role play and feel comfortable with conducting the interview. Less time left for this, so in the end we had 20 minutes each then swapped.

In the future, I need to make sure I am organized with the group. This has slipped slightly recently and was noticeable in this session. Also, I need to find out who M's case worker is. I don't know why I didn't previously pick up that M has received services from this team?⁸⁹ S is receiving services from the South team, so I will need to ensure all her interviews are within the north team. I have raised the issue of confidentiality with both M and S, and ensuring that interviews are conducted in the alternative team should eliminate any potential issues of knowing the participant / people being discussed, in the interviews.

Recruitment challenges

April 2011

Although active and productive, April was also a month where insecurities, doubts and larger concerns have raised their head. I was excited and nervous about actually going to meet the practitioners in the CMHT – these are the people who will be instrumental to this project's success. A couple of weeks later and my worries have increased. I have had no responses following the initial presentations and have had to cancel my 'recruitment evening for SUs' because flyers were not handed out, as requested. Barriers seem to be present in starting the data collection process. Following my conversations with the team leaders, I get the impression that getting numbers to anywhere near where I want them is

⁸⁹ I have followed this up: M actually receives services from another team, so this is no longer needs consideration in the interview planning

not going to be an easy task. My main worry is the TLs. They do not seem to want to promote this project for me, and there is a sense of lack of ownership, such that it is very much up to me to try to engage each person individually, without senior backing. I do not think this is a brick wall but I suppose I would have liked this phase to have been slightly more productive. What to do next? Persevere and aim for a snowball effect. I need to build interest and confidence with each practitioner in the team.

September 2011

Recruitment has progressed over the summer months, but at a slow pace and only with practitioners. I am not making any progress with service user recruitment. In September, I again contacted the team leaders to promote service user recruitment. I have had to compile more leaflets, and now have decided to leave these in reception. I have also asked a TL to do a postal send out. Again TL appears very supportive, but following this I still do not know if the information is in the hands of service users or whether the TL has done what she promised.

Conducting interviews

September 2011

Reflection following the first SU pilot interview. This was a useful exercise. S led and I shadowed. Difficult customer: he practically did not answer one question. I felt he was quite aloof and was over thinking some of the questions. He also had an agenda for being there, to share and reflect on his experience and views and was using this opportunity for this purpose. Any reference to decision making was medicalised, e.g. decisions based on serum levels. Interesting in one sense in that little reflection of acknowledgement of involvement in decisions, and happy to follow recommendations made by the doctor. S did a good job of sticking to script and maintaining rapport. But given the difficulty of the interview, my approach would have been different. I would have gone off script and just tried to pull out relevant information by probing on relevant bits. I gave this feedback, to have confidence, to build on what the participant says and to draw more out. But it was difficult for me to give this advice as this will result in less structure and consistency, especially across the full co researcher group. I think I have to manage this on a one to one basis: for some co researchers, more structure, stick to script, for others less. I have also realized that some questions need to be reworded. So this was a useful exercise.

On related point, my interview with a CPN yesterday was an interesting one with some strong views and recommendations expressed. She was very passionate about her work and how to make things better and would often use the questions as an opportunity to talk more widely about mental health services and her views about what improvements are necessary. SDM model came across strongly as her ideal, although once again very much sitting in a larger therapeutic relationship. She also did talk about women and the female aspects a number of times and there seemed to be a gendered discussion with some of what she was saying – I did also feel there was a motherly aspect to what she found important. The examples were interesting in that firstly success involved coming off psychiatric meds and going on instead to very low dose depot. Example of failure focussed on not being able to get someone off high dose meds (because psychiatrist wouldn't agree with her). First observation : both examples demonstrated her negative attitude towards psychiatric medication. Possibly more interestingly, both examples were centred around

her role, as a CPN and being in control / not in control. She did not touch on SU empowerment/ownership in any obvious way – it was instead about her knowing what was best and seeing that through (or not in the failure example) for the best of her clients – so actually both examples had a strong maternal element.

My reflections following this interview was that it was more emotionally charged than I had been prepared for. The passion in her responses was apparent, and there were a couple of occasions when I thought she was hiding back a tear. This affected how I found the interview, at times, I found it emotionally challenging. I did feel like a fuller debrief was necessary following this interview (for me, but also importantly, for her). I reflected that until this point I have been mostly concerned with the ethical concerns for service user interview experience and potential distress. However, I am beginning to think that instead practitioners are actually finding this process more distressing in a number of ways. Whereas possibly service users are used to talking about what has happened to them and appreciate talking about their views, practitioners perhaps have less opportunity to reflect, take a step back and think about what is particularly important etc. I think the practitioners are perhaps finding these interviews difficult. I have not been consistent with the debriefing aspect of the interview and think I need to be far more mindful of this going forward. However, this is not only because I had not realized the potential ethical impact for practitioners, but also because of deeper issues around roles and responsibilities. I am the naive and external researcher interviewing trained mental health professionals. In a way I find it embarrassing and patronizing to ask: are you ok? to people who are used to doing this everyday in their own jobs. I also think practitioners prefer the distance and to remain in the 'professional' role. Having said this, I do think I at least need to acknowledge more openly the ethical – distress elements explicitly post interview.

November 2011

First interview with M and service user participant. I led, M shadowed. Another interesting interview. Some strong themes are emerging from these interviews. I was worried that people may get dragged off track and present their life story, and although this happens it doesn't dominate and remains focussed on topic. Happy with M's performance. He was nervous and again lacked confidence, but when encouraged, the question he asked made a large contribution to the interview and really helped bring the interview back to the area. I think he has good interviewing skills. Only potential problem is tiredness – he has said he found it very tiring and I do think the interviews are rather on the long side: need to be mindful of this.

Initial reflections from interviews and coding process

September 2011

CPNs

Some differences between interviews are now becoming apparent (5 interviews with CPNs only).

Models of ideal working (in terms of involvement in decision making) – some themes from some interviews around empowering clients to take lead in decisions, giving them the skills to be able to make informed choice and learning skills to know how to go about helping themselves. So med mgmt in this sense fits in with larger therapeutic role and a

focus on self management. This is also in tune with pathway strategy where after 18 months you are on your own. There is also acknowledgement of clients being the decision maker with clinicians 'backing off' if someone is set on something. However, in the same breath, practitioners always give opinion and keep suggesting what they think will work. But if this is different to client, that is not necessarily an issue, seen as a learning experiment and a trial and error process. Honest open and trusting relationships key.

Some examples of success include descriptions about when the client leads the way, even if different from practitioner. Some examples of failure centre on when the conversation was not real. I.e. fears SU not open or telling truth, - this seems to be the hardest situations for practitioners to handle. One example talks about how they just back off, don't bother pushing it if that is the case. However in other interviews a far more maternalistic/paternalistic approach comes across – directive, expert, supportive, thinking about the longer term. Need to look at these interviews a bit more see where the links across are.

Note to self – it would be useful to share some of the transcripts with Shula, Nicola and Carol. I would like to get their impressions of some of these interviews (one of each stakeholder group) to assist initial analysis. Is this appropriate or not? Is it perhaps better for me to lead this at this stage?

January 2012

Initial notes following an interview with a psychiatrist

Key notes whilst transcribing Cons Psych 1.

P.5. regular appointment 'fundamentally unhelpful' (i.e. in response to views surrounding reduction in continuity of care in psychiatrist role)

'How they are doing' job of other professionals'

P. 6 "yeah, well on the whole, except for a few rather rare circumstance, uh, I think they are kind of absolutely involved because they are the ones who have to take it"

P. 7. Side effects - better to discuss upfront rather than for the service user to find out afterwards and then talk about it

P.7. Sensitive information - telling people about sexual side effects

P.8 Presenting choices. Admits choice often limited and use of 'but 'to rule out certain choices in conversation

Options sometimes presented as a plan b - i.e. if this doesn't work, next step options 'go away and we can meet next time' [but how does this fit with not holding routine appointments']

Barriers

P.10 people lying as affecting involvement

Fear of being taken to hospital if admits not taking meds [lack of honesty related to fear of coercion]

Being involved as a tool for encouraging compliance?

How giving information is part of "involvement"

P. 11 Thinking about long term solutions

P.13 Meeting of success - "him having his plan, me having my plan" I explained why his less likely to work. Outcome, left him to decide "he can kind of do what he wants really" [persuasion] "took into account not just the tablets but also his kind of wider life"

P.15. Negative example

Not understanding the person and feeling not connected - i.e. "but particular to me" - not same to other practitioners. Having two conversations

Not meeting "never quite meet the conversations"

P.16. lack of shared understanding

role of carer - another pair of ears.

- but also can make relationship more fraught,

-coercive relationship.

-wider social environment. carer also affected.

Notes from interview with CPN

'You become like a well-trained sniffer dog. You see things, you notice'.

Go between.

Other evidence and supporting people full you in on their experience.

P.4 Legal consequences for not listening, not explaining.

Role of meds

"travesty of human justice really"

P5: Its important to find out, so you can use those as a leverage to be able to support and listen and advise and yet encourage concordance.

-barriers to concordance - system factors

- Want people to tell you when not taking prescribed medication, but at same time still encourage compliance as you have a responsibility (risk versus empowerment),

P.6 Different info within and outside services

P7 Share but personalised

Reinforced revisit

P7. reference to ongoing experiment. 'kept going until we found somebody who was willing to listen'

P8 First para - important factor influencing involvement class, background

Role of carer,

P8 - role of meds

P11 - Success. "Walking the journey together" Pulling and pushing

'But actual what's integral to it is first of all, winning somebodies confidence and trust'.

Reflecting on this transcript

In terms of initial reflections on content and important themes

*Role of meds and the morality of psychiatric medication strongly presented throughout. Also the desire for greater accountability

* Involvement as walking the journey together, as trust and caring for the person and the therapeutic relationship.

*The role of the CPN - The importance of having an opinion and being brave enough to enter conflict with other practitioners about decisions. Being a voice / advocate for the service user.

* Some aspects of enhancing control to the service user were talked around as important aspects of decision making, mainly in terms of providing information.

More strongly, I felt this transcript was about the importance of caring and treating people with dignity and protecting people from aspects of the system and feeling. The priority for psychiatric medication management was about having a real understanding of the person and care of the person.

*This doesn't necessarily fit with SDM as an ideal.

April 2012: Creating structure

Creating the conceptual themes: I am now trying to separate out the conceptual and the structural (or functional, need to check correct language for this) coding framework. I found drawing a mind map especially helpful in which initial themes are presented from the list of nodes for 'conceptualising involvement'. I have grouped the list into 9 themes, with codes underneath and this does help.

I am still struggling to incorporate examples of success and failure into the conceptual framework. I think I am stuck and unhelpfully hanging on to the idea that this section of the interview is somehow qualitatively different, and hence needs separating from the general question section of the interview. It is helpful to remember the research questions: data from the interviews is only useful as directly exploring this. Therefore complicating the coding by keeping success and failure separate is not useful. Having thought about this I am proceeding to keep the idea of positive and negative, but pooling content under the previously coded themes.

June 2012 - Lack of insight

Lack of insight as a barrier mentioned by 2 / 13 SU interviewees. This is compared to 5 or 6 / 7 psychiatrists and 4/8 CPNs. I need to return to the transcripts and check this.

Being in crisis is described as a problem for SDM by most SU interviewees, especially in terms of problems of concentration, being able to focus on information at the time, and not feeling in 'right place' to make decision. I wonder if this difference in emphasis needs to form part of write up? Esp. in the context of a CMHT?

June 2012.

Barriers

The morning has been spent building themes within the barrier node. I feel happy now the nodes are a useful way of exploring barriers talked about by service users. Interestingly, the two most frequently mentioned sub theme nodes 'About the service user'. 31 refs (being in crisis vs lack of insight - see memo above) and ' power and control' 22 refs. I think an important aspect of the write up and discussion will be centred on how to bring together these two components.

Choice

I need to re examine 'choice'. For the service user data, there doesn't appear to be enough nodes, to pull this as an overarching theme.

July 2012.

I have started to write the findings in time for my next supervision in a couple of weeks or so.

I think it is useful to think of this as a way of assisting the analysis. It is through writing that some clarity may emerge. The first difficulty in embarking on this process, however is how to structure the chapter?

After some thinking and reading other findings chapter, I emerged with the idea of presenting the findings of the interviews in layers, similar to the diagram suggested for the social science and medicine article. I can split the key themes, as coded in n vivo according to the 3 layers, system and structural, relationship and conversation. This will be presented for each stakeholder group and then a separate analysis section on exploring important differences and similarities.

I like it, feel it makes a lot of sense for what we are exploring and helps make apparent the complexity. By not using such a framework I run the risk of creating a very messy picture with a long lists of findings for each stakeholder group without a framework to guide them.

August 2012

Version 1 of the findings chapters adopts a three layer approach: the conversation, the relationship, the system, incorp. diagram. This represents the overarching data themes in a better way than mere subtitles for examples, barriers, facilitators etc. The three layers

can explore the data driven themes for each layer.

But I also want to return to the transcripts and focus on these question responses from the interview:

What is the role of the psychiatrist?

In an ideal world, how would you prefer for decisions to be made about your medication?

Are there problems with involving people in the decisions about their medication?

In particular, this may be useful for exploring the differences between stakeholder groups. I will code these questions in the structural coding folder and examine again.

Excerpt following collaborative analysis meeting (also see appendix VII)

October 2012

The collaborative analysis meetings have started and are proving very insightful and enjoyable sessions. From my perspective it is really good to hear other people's perceptions and interpretations of the transcripts and it has resulted in me going back to the initial coding and reemphasising certain aspects (e.g. continuity of care, practitioner as going above and beyond). The team dynamics of the meeting are interesting too. The session (SU3 transcript) was a good example of this. I did notice that certain participants in the group were more likely to assert their interpretations quickly and contribute to the meeting than others, but I found that by formally asking each person individually, this helped ensure that everyone did contribute. People in the group appear very comfortable and we all consider ourselves friends and colleagues now, as oppose to performing a certain role. At times it was necessary to seek clarification about the point in relation to the transcript, as some themes were poignant to group members own experiences and there is a tendency to move into a more general discussion. The other aspect to consider was the dynamic between the practitioner member of the group and service user members – at times I felt group members continually were seeking affirmation from the practitioner member and that the practitioner member would sometimes act in their CPN role as oppose to a co researcher for this project. I have spoken to xx about this, and he does reflect that often he has to rush straight to the meetings from work so it is hard to switch mind set quickly. But in general and most of the time, all members appear very comfortable with being researchers, passionate about the research and topic, as oppose to merely representing their profession / identity as service user/carer.

Appendix III. Interview schedules

Service user interview schedule (co researcher script)

1. Opening the interview

Introduce yourself

Your first name and little background (where you receive services/ your spouse receives services (if carer)).

Hello, my name is xxx. I am a current / former service user / carer and I/my spouse receive services from xxx. I am here today to ask you some questions for a research study.

A reminder about the study

'The study is about how mental health professionals and service users discuss and make decisions about psychiatric medication. We want to find out about people's views and experiences of being involved in decisions about medication they have or don't have. We think there is more than one way of coming to a decision so we are not looking for the right or best way for making decisions. We know that different ways will suit different people. We would like to hear about your experiences and your opinions about things like how you and the mental health professionals talk about medication and making decisions about this.'

Check consent

Did you receive the information sheet? Have you signed the consent form to participate in the research?

If not, **STOP**, give a copy of the information sheet, ask again if they have seen this before, check *have you seen this before?* check notes, call Emma if appropriate. **DO NOT PROCEED WITHOUT CONFIRMING THEY HAVE GIVEN WRITTEN CONSENT.**

Confidentiality and Format

Please talk about what you feel comfortable with (has control over what information is disclosed). We can stop at any time if that is what is preferable or take a break. Everything that is disclosed in the report will be made anonymous so you cannot be identified. This study has nothing to do with any services you receive and is independent.

Friend or supporter present?

Because we only have a limited time, I may need to ask you at some point to stop talking so we can proceed with further questions. Please do not be offended if I ask you to do this, I am just very keen to make sure I can get as much information from you as possible in the time we have.

Permission to record

This is a digital recorder which I would like to use to record our meeting. Is this OK?

If unsure, explain, this is only being used so that we can make sure we capture everything you say, otherwise I might forget to include something which may be important in the analysis of the data later. When it is analysed it will be made anonymous and you will not be identified in the report.

If still unsure, ask why this is causing a problem? If not easily resolved at this point, explain you will need to stop the interview and reschedule at a later date or

cancel it as you do not have the resources to do the interview without the digital recorder. Apologise and close interview

Agree time to finish.

This should take around one hour. Is this time OK with you?

1. Background information

NOTE: SHORT CLOSED QUESTIONS

If I can just take some basic details first:

Age:

Male / female:

Are you currently in receipt of psychiatric medication? Yes / No

In general, approximately how long have been in receipt of medication (years or months – total time and on / off if appropriate):

NOTES: names of meds if known:

2. Making decisions about medication

NOTE: BRIEF UNDERSTANDING OF HOW PSYCHIATRIC MEDICATION DECISIONS ARE MADE and WHO MEDICATION IS DISCUSSED WITH

Firstly, I would like to understand more about the people you talk to and how decisions are made about your psychiatric medication (N/B this may include decisions around not taking medication, also).

Can you tell me then, how are decisions made about your psychiatric medication?

Who do you talk with when decisions are made about your medication?

PROBE: Who is in the room: Psychiatrists, CPN etc?

How often is a decision made about your psychiatric medication?

PROBE, how often are things like for example changing the dose, the type of medication or even when deciding to stay the same

How often do you talk with the above people about your psychiatric medication, but no decisions are made,(with each person above)?

What role do you play in making decisions about your psychiatric medication?

What role do you think the psychiatrist plays in making decisions about your psychiatric medication?

What role do you think the nurse plays in making decisions about psychiatric medication?

Who usually makes the decision about your psychiatric medication?

Do you have an advance directive in place?

(That is have you specified what you would like to happen if you have a crisis and what treatment you would like or not like in these situations?)

*Are there other people involved in the process of making these decisions about psychiatric medication?
(For example, carers, social workers, pharmacy services)*

Are some meetings more difficult than others for you to be involved in decision making about your psychiatric medication?

PROBE: Does your being involved in the decision making about your psychiatric medication depend on anything?

*Have you learnt anything which helps you in meetings where psychiatric medication is discussed?
What? and how does this help?*

Is there anything you would find useful to you when your psychiatric medication decisions are being made?

3. Participation in Consultation - General

USE PROMPT SHEET IF NECESSARY

I would like to explore now your general views of how people are involved in making decisions about their psychiatric medication.

Preferences for decision making

In an ideal world, how would you prefer for decisions to be made about your medication?

PROBE: How involved would you like to be in decisions about psychiatric medication? See PROMPT sheet

Does this preference for how you would like decisions to be made depend on anything?

PROBE: Are there times or certain things which would change how involved you would like to be in decisions about psychiatric medication?

Do you think your preference for how decisions should be made is typical for other service users too?

If yes is there anything about your view which is different to others in your opinion?

If no, why not?

In general, what are the problems (if any) with involving people in decisions about their medication?

4. Defining moments and some examples.

NOTES: DETAIL IMPORTANT> FOCUS ON RECENT MEETING OR EVENT. IF STARTS SPEAKING MORE GENERALLY, PULL BACK TO THE PARTICULAR EVENT. ANSWER 2 out of 3, ONLY.

For each question, try to think about:

- Range of options
- Identify decisions
- Identify points of involvement
- What factors make it memorable

OPTION 1: Example of success (positive example).

*I would now like you to take a minute to think of a specific time **in the last 6 months** (a meeting for example) which sticks in your mind **when you felt good** following a decision was made about your psychiatric medication?*

PAUSE. WAIT FOR ANSWER. IF Struggling move to OTHER 2 QUESTIONS BELOW

PROMPTS:

OK, can you tell me about this time/meeting:

Who was the meeting with? How long have you known them? Do you have a good relationship?

When was it?

So what was the meeting about? Who brought up the conversation about the psychiatric medication? What did you say? What did they say? And how did that make you feel? OK, so then what happened?

So were different options talked about? What decision was made?

So what was it about this meeting which you think made you feel good? Why?

What did you expect before the meeting? Were these met during the meeting?

Did something happen in the meeting you didn't expect?

If you were to have this time again (meeting) would you do anything differently?

OPTION 2: Negative example.

*I would now like you to take a minute to think of a time **in the last 6 months** (a meeting for example) which sticks in your mind when **you felt not good** following a decision was made about your psychiatric medication?*

PAUSE. WAIT FOR ANSWER. IF Struggling move to ALTERNATIVE BELOW

PROMPTS:

OK, can you tell me about this time/meeting:

Who was the meeting with? How long have you known them? Do you have a good relationship?

When was it?

So what was the meeting about? Who brought up the conversation about the psychiatric medication? What did you say? What did they say? And how did that make you feel? OK, so then what happened?

So were different options talked about? What decision was made?

So what was it about this meeting which you think made you feel good? Why?

What did you expect before the meeting? Were these met during the meeting?

Did something happen in the meeting you didn't expect?

If you were to have this time again (meeting) would you do anything differently?

OPTION 3: Defining moment. Brief exploration.

Is there one meeting or time that you particularly remember, (either positive or negative), which sticks in your mind and involved making decisions about your medication.

PAUSE. WAIT FOR ANSWER.

NOTE: Use prompts (same as above questions) if appropriate

If you were to have this time again (meeting) would you do anything differently?

6. Closing

1. Thank you very much for your time and your comments.
2. Do you have anything else you want to say/ask?
3. This has been very interesting/useful/helpful..
5. Remind about confidentiality.
5. Arrange next time to meet- or state when I will contact them again.

We will also be looking to invite people who participated in these interviews to a discussion group later in the research process, would this be OK if we contact you about this in the future (few months time)?

6. Debrief: reaffirm purpose of research, check reactions and wellbeing. Give out information sheet with useful contacts if person has questions about their medication and/ or refer back to care team.
7. Transcript to be looked at for accuracy?
Would you like to receive a copy of the transcript of this interview so you can check it is accurate or are you happy not to receive this?

Practitioner – Interview Schedule and Topic Guide

Date

Time

Male / female.

Interviewer comments:

Length of time in position and experience.

Opening

- Introductions
 - Name, role and institution and little background (2 sentences)
 - This research is completely independent to mental health service provision
- Reminder of what study is about
- Confidentiality
- Free to talk about what feels comfortable with (has control over the information disclosed).
- We can stop at any time if that is what is preferable or take a break.

- Friend or supporter present?
- Permission to record?
- Agree time to finish.

Possible starter:

Can you tell me a bit about you and your background in ...
(length of time in profession/ speciality ; ?training; age)

Background questions

- Overall approach to consultations and any differences to other practitioners
- Changes in approach to consultations over time
- The value of medication in mental health treatment programs and recent changes

Participation in Consultation – General

Can we talk a bit about your views about how people are involved in making decisions about their medication, in general.

- *Role in decision making process. Factors that affect this.*
- *Preferred level of involvement with patients in decision making*
- *Examples of strategies used to involve patients in decisions*
- *Level of information provided to patients and factors affecting this*
- *Selection of treatment options*
- *Factors affecting ability to involve patients in decisions*
- *Views on role of the carer in the decision making process*
- *Views towards patient participation*
- *Benefits participation offers*
- *Barriers to participation*
- *Suggestions for assistance in decision making process (training, support, etc)*

Decisions in Consultations. Exploring defining moments and examples.

It would help me to get an idea of the process you go through in a consultation which involved making decisions about medication. Could you tell me about a typical consultation (if there is such a thing)

- Range of options
- Identify decisions
- Identify points of involvement
- What factors make it memorable

PROMPT: or think of an example of a service user you saw recently and talk me through the consultation

- Range of options
- Identify decisions
- Identify points of involvement

Example of success (positive example).

Can you give me an example of a recent (last 3 months) consultation which you felt resulted in successful decision being made about medication?

- Context. Existing relationship with client, decisions made, process of meeting and exploration of what decision was made?
- Reasons for success

- Step by step process
- Role in the decision
- Factors which helped achieve success
- Barriers and how overcome
- Expectations and fulfilment

Negative example.

Can you talk through a consultation which you felt was not successful in terms of making decisions about medication?

- Context. Existing relationship with client, decisions made, process of meeting and exploration of what decision was made?
- Reasons for disappointing outcome
- Step by step process
- Roles in the decision
- Factors affecting disappointing outcome
- Barriers and how to overcome

Closing

1. Thank you very much for your time and your comments.
2. Do you have anything else you want to say/ask?
3. This has been very interesting/useful/helpful..
4. Statement of confidentiality.
5. Arrange next time to meet- or state when I will contact them again.
6. Check transcript for accuracy?

Appendix IV. Removed OPTION scale analysis (phase two)

OPTION Scale : Initial analysis of phase two data.

This analysis has been removed from the thesis.

The OPTION (Observing Patient Involvement) scale (Elwyn et al, 2003) was originally chosen for the analysis as it explores the extent to which practitioners engage patients in decisions about medication and undertake competencies seen to be required for shared decision making. This instrument demonstrates acceptable reliability (Cronbach alpha - 0.79). This scale was designed from a set of competencies seen to be requirements for SDM and has received much attention in the broader health care SDM literature. I thought the use of this tool might assist with the exploration of the extent of SDM in psychiatric medication management practice, for phase two data. Initial analysis undertaken on the recorded meetings is presented below.

ITEM	strongly agree	agree	neutral	disagree	strongly disagree
(1) The clinician identifies a problem(s) needing a decision making process		X	X X	X	
(2) The clinician states that there is more than one way to deal with an identified problem ("equipoise")			X	X X	
(3) The clinician lists "options" including the choice of "no action" if feasible		X X		X	
(4) The clinician explains the pros and cons of options to the patient (taking "no action" is an option)		X		X X	
(5) The clinician checks the patient's preferred information format (words/numbers/visual display)				X	X X
(6) The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed		X X X			
(7) The clinician explores the patient's concerns (fears) about how problem(s) are to be managed		X X	X		
(8) The clinician checks that the patient has understood the information		X	X	X	
(9) The clinician provides opportunities for the patient to ask questions	X	X X			
(10) The clinician asks for the patient's preferred level of involvement in decision making					X X X
(11) An opportunity for deferring a decision is provided	X X	X			
(12) Arrangements are made to review the decision (or the deferment)	X	X X			

KEY- SERVICE USER NAME (pseudonym):

X - ROSIE

X - LARA

X - LINDA

X - CARL

Using this measure some skills are employed by the psychiatrist in three out of four meetings, including: exploring the patients expectations or ideas about how the problems








are to be managed, giving opportunities to ask questions, and allowing an opportunity for the decision to be deferred. Arrangements to review the decision are also made for Rose, Lara and Linda. However for Lara, there is no presentation of options and no pros and cons of options are presented. On the face of it then, it would appear that Lara was being less involved than other participants (- Carl, who is discussed later). This does not fit with the conversation analysis undertaken, where Lara displayed strikingly more assertive dynamic than the other service users. If we explore this further an obvious explanation emerges. In Lara's meeting, there is little in the way of a direct 'problem' as described by Elwyn et al in their descriptions of the SDM process (Elwyn, 2003; Charles et al, 1997). In fact, much of the conversation with Dr Kos and Lara centres around Lara's recent improvement in mood, with Dr Kos often making comments that there is much improvement. As such according to this narrow definition of SDM, a problem, as described in item one, does not exist, thereby making many of the subsequent items irrelevant. However a decision around medication was made at this meeting, where Lara increased her dose of Lamotragine, even though a particular 'problem' was not directly referred too. Instead, and in fact, this meeting involved the discussion of other physical symptoms, including memory loss , concentration problems and skin conditions, which may have been a side effect of the medication. However this was not seen as a 'problem' by the psychiatrist and no decision making around these problems were entered into by either participant.

Carl's meeting could also not be directly coded further than item one, using this scale. In Carl's example, again, no problem was identified and whilst a review of the medication was undertaken, no change was made at this meeting. So according to this measure, this meeting does not emerge as requiring SDM.













One observation from this analysis is the apparent lack of fit of such a measure to exploring SDM for medication management practice in mental health. The importance of exploring the context of the meeting, and the expectations of both participants, not just the behaviours of the practitioner, is apparent through this analysis, and the ticked boxes above do not really enhance our appreciation of collaborative medication management. As such this analysis has been removed from the main thesis.

Appendix V. N vivo data driven coding framework













CPN parent nodes

	Name	References
	Choice	4
	Barriers	18
	Facilitators	25
	Power	11
	involvement spectrum	34
	Relationship	31
	The conversation	33

Psychiatrist parent nodes

	Name	References
	Barriers to involvement	46
	Choice	44
	Decision making process	36
	Desire to involve SUs	1
	Facilitators	37
	Involvement spectrum	8
	Meeting of experts	15
	Miscellaneous	2
	Power	11
	Process over time	11
	relationships	18
	SU empowerment	11

Service user parent nodes

	Name	References
	Barriers	 104
	Choice	 5
	Facilitators	45
	Involvement spectrum	 48
	Other sources of information	16
	Power	21
	Process over time	20
	relationships	22
	The conversation	49

CPN first stage coding

cpns

Name	References
<input checked="" type="radio"/> Choice	4
<input type="radio"/> Barriers	29
<input type="radio"/> System barrier	13
<input type="radio"/> ethical and moral	1
<input type="radio"/> Short term focus, reactive, crisis resolution	1
<input type="radio"/> locus of control	1
<input type="radio"/> dominance of medical model	6
<input type="radio"/> ad lib administering , lack of accountability	2
<input type="radio"/> pressure for doctors to prescribe	2
<input type="radio"/> cultural norms	1
<input type="radio"/> Mental health act	1
<input type="radio"/> CPN not able to make changes	1
<input type="radio"/> Depends on psychiatrists how much involvement from other people	1
<input type="radio"/> About the service user	15
<input type="radio"/> being passive recipient	3
<input type="radio"/> being passive recipient	3
<input type="radio"/> SU doesnt want to be involved. Let the doctor decide.	2
<input type="radio"/> class	1
<input type="radio"/> Deception	2
<input type="radio"/> intelligence ability	1
<input type="radio"/> severity of illness	7
<input type="radio"/> withdrawn	1
<input type="radio"/> Insight	8
<input type="radio"/> not understanding role of medication	1
<input checked="" type="radio"/> Facilitators	20
<input type="radio"/> Miscellaneous	1
<input type="radio"/> carer	3
<input type="radio"/> Tools	0
<input type="radio"/> Internet	1
<input type="radio"/> Homan's drug attitude inventory	1
<input type="radio"/> Advance directive	1
<input checked="" type="radio"/> relationship factors	11
<input type="radio"/> therapeutic relationship	3
<input type="radio"/> mutual respect and affection	1
<input type="radio"/> knowing and caring about the person	1
<input type="radio"/> Being honest	2
<input type="radio"/> trust	1
<input type="radio"/> remaining engaged	1
<input type="radio"/> setting expectatins	1
<input type="radio"/> keep regular contact	1
<input checked="" type="radio"/> system factors	5

cpns

Name	References
<ul style="list-style-type: none"> emphasis on psycho social model of understanding. <ul style="list-style-type: none"> acknowledging complexity bio psycho social increased accountability and signed consent Structural factors <ul style="list-style-type: none"> SU being assertive, articulate, bright Class and being articulate Communication factors <ul style="list-style-type: none"> language reinforcing information Power <ul style="list-style-type: none"> Carer as powerful Professional accountability and responsibility persuasion SU power not to take meds involvement spectrum Relationship <ul style="list-style-type: none"> walking the journey being an advocate Honesty Trust Being listened to when ill personality setting expectations The conversation <ul style="list-style-type: none"> negotiation, building consensus backing down, waiting to see Information giving <ul style="list-style-type: none"> Information withheld <ul style="list-style-type: none"> changing language Long term side effects shortened life expectancy difficulties coming off Is selective It varies Could be better Types of information <ul style="list-style-type: none"> Side effects Depends on SU preference. SU not wanting all info Its a conversation Information seeking 	<ul style="list-style-type: none"> 2 1 1 2 1 1 0 2 4 11 4 1 3 1 34 31 12 1 8 4 2 1 1 34 4 4 18 5 1 2 1 1 2 1 2 6 3 2 5 2

cpns

Name	Sources	References
Internet	2	2
meeting of experts	5	9
Types of knowledge	4	6
<ul style="list-style-type: none"> SU knowledge and needing to listen CPN expressing opinion 	<ul style="list-style-type: none"> 2 3 	<ul style="list-style-type: none"> 2 4

Psychiatrist first stage coding

psychiatrists

Name	References
Involvement spectrum	18
paternalistic	11
Involvement as encouraging compliance	10
compliance links to involvement	3
Information withheld	5
SDM	6
informed	1
Barriers to involvement	48
system barriers	6
chronic care or long term care as barrier	1
Fear of coercion as barrier to involvement	5
carer	4
Not useful information	3
the internet	1
experiential information. Opinion	1
Structural	2
Time	1
Stress	1
About the service user	15
Lack of insight	8
Insight not a barrier	1
Dementia	1
Capacity to consent	4
Severity of illness	1
unrealistic expectations about medication	1
Communication factors	12
not understanding the person	6
no sharing of conversations	4
Deception	2
Choice and SU Ownership	55
Weighing up	8
options and presenting choice	25
Information	10
choice is limited	1
SU empowerment	11
Decision making process	37
information seeking	13
Monitoring	2
thought processes or things prior to the conver	5

psychiatrists

Name	References
<input type="radio"/> information giving	12
<input type="radio"/> Desire to involve SUs	1
<input checked="" type="radio"/> Facilitators	37
<input type="radio"/> benefits of involving carers	9
<input type="radio"/> examples of success	1
<input type="radio"/> Overcoming barriers - facilitators	1
<input type="radio"/> benefits of involving carers (2)	5
<input type="radio"/> therapeutic relationship	1
<input type="radio"/> advance directives	1
<input type="radio"/> Trial and error, seeing it as an experiment	1
<input type="radio"/> not talking about diagnosis	1
<input type="radio"/> About the interaction	12
<input checked="" type="radio"/> Meeting of experts	15
<input type="radio"/> meeting between experts	5
<input type="radio"/> SU having knowledge about medication	1
<input type="radio"/> Su being part of team	1
<input type="radio"/> Shared conversation	1
<input type="radio"/> SU preferences and values	4
<input type="radio"/> consensus not necessary	2
<input type="radio"/> Miscellaneous	2
<input checked="" type="radio"/> Power	11
<input type="radio"/> Information withheld	6
<input type="radio"/> persuasion	5
<input checked="" type="radio"/> Process over time	11
<input type="radio"/> Walking the journey together	1
<input type="radio"/> Giving time to think	4
<input type="radio"/> Past experience	4
<input type="radio"/> Taking time to reach decisions	2
<input checked="" type="radio"/> relationships	18
<input type="radio"/> Flexibility in communication style	4
<input type="radio"/> individualised approach	2
<input type="radio"/> positive talk	5
<input type="radio"/> Being honest and open	1
<input type="radio"/> knowing the person - relationship	1
<input type="radio"/> presenting balanced picture	1
<input type="radio"/> Rapport	1
<input type="radio"/> Conflict	1
<input type="radio"/> negative talk	7
<input type="radio"/> Coercion	1
<input type="radio"/> not understanding the person	6
<input type="radio"/> Importance of practitioner as person	0

Service user first stage coding

service users

Name	References
Involvement spectrum	48
It varies	6
wanting stronger guidance in crisis	2
SU not wanting too much responsibility	4
involvement as letting me decide	2
who makes the decision	1
service user makes decision	6
Psychiatrist	6
Joint decision	5
fairly involved	3
paternalistic	12
compliance	2
no involvement no choice coercion	4
SU having control	12
Shared	8
Being informed as involvement	3
informed model SU ownership	5
Ideal world	1
Choice	5
Be good to have more choice around not taking m	1
too much choice	2
Preference not expressed	1
Power	23
coercion	10
being persuaded to take meds	2
SU power	4
passive resistance	2
doctor patient power	4
Process over time	20
relationships	22
Honesty	3
difference of opinion team working	1
Going above and beyond	1
Building partnership over time being more involve	2
trust	13
Barriers	104
stigma labelling	10
System barriers	12
About the service user	36

service users

Name	References
<input type="radio"/> crisis - being ill	34
<input type="radio"/> lack of capacity	2
<input checked="" type="radio"/> Power and Control	25
<input type="radio"/> Felt like a child	5
<input type="radio"/> Spoken down to	7
<input type="radio"/> Fear of coercion	8
<input type="radio"/> Being ignored talked about not to	2
<input type="radio"/> Lack of control	3
<input type="radio"/> About the conversation	16
<input type="radio"/> Relationships	5
<input checked="" type="radio"/> The conversation	49
<input checked="" type="radio"/> Facilitators	69
<input type="radio"/> Honesty	6
<input type="radio"/> Gaining knowledge	13
<input type="radio"/> seeking knowledge	3
<input type="radio"/> self awareness self monitoring	3
<input type="radio"/> making plans	1
<input type="radio"/> About the conversation	26
<input type="radio"/> Information seeking	1
<input type="radio"/> Practitioner skills and behaviour	24
<input type="radio"/> using closed questions	3
<input type="radio"/> sitting close and clear language	1
<input type="radio"/> personalised language	3
<input type="radio"/> Listen	3
<input type="radio"/> practitioner reading notes history but keep	1
<input type="radio"/> Information presented in clear concise wa	2
<input type="radio"/> being told what happens if it doesnt work	1
<input type="radio"/> being given information, not having to alw	8
<input type="radio"/> being asked best and worst outcome at st	1
<input type="radio"/> Reading non verbal behaviour	1
<input type="radio"/> feedback	1
<input type="radio"/> Relationships	13
<input type="radio"/> CPN as go between	1
<input type="radio"/> Reassurance from practitioner (reducing fear	1
<input type="radio"/> CPN as mentor offering therapeutic help in co	1
<input type="radio"/> GP and postive relationship	3
<input type="radio"/> Carer and friend support	2
<input type="radio"/> Respect	4
<input type="radio"/> age of doctor	1
<input type="radio"/> System	3
<input type="radio"/> Increased communication between doctors a	3

service users

Name	Sources	References	Created
<input checked="" type="radio"/> Tools and techniques	3	5	02/07/2
<input type="radio"/> advance directive	1	1	28/05/2
<input type="radio"/> Blood test	1	1	21/06/2
<input type="radio"/> CBT techniques	1	1	28/05/2
<input type="radio"/> Information sheets in table form	1	1	21/06/2
<input type="radio"/> follow up letter	1	1	27/08/2
<input checked="" type="radio"/> Other sources of information	9	16	23/0/
<input type="radio"/> Internet	7	7	23/05/2
<input type="radio"/> second opinion	1	1	24/05/2
<input type="radio"/> family or friends	2	2	20/06/2
<input type="radio"/> Other MHSUs	1	1	20/06/2
<input type="radio"/> leaflets	3	3	21/06/2

Appendix VI. NHS Research Ethics letter of approval



National Research Ethics Service

Hertfordshire REC

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597597
Facsimile: 01223 597645

14 January 2011

17 February 2011 - sent again to Emma Kaminskiy only with revised address and copy to home address

Mrs Emma Kaminskiy, PhD student
Anglia Ruskin University
Helmore Building, Room 308
East Road
Cambridge
CB1 1PT

Dear Mrs Kaminskiy

Study Title: Exploring collaborative psychiatric medication management. An examination of service users and clinicians attitudes, values and behaviours.
REC reference number: 10/H0311/58
Protocol number: N/A

Thank you for your letter of 14 December 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Reply Slip	2.3	04 November 2010
REC application: IRAS parts A&B 56044/162836/1/982		08 November 2010
Evidence of insurance or indemnity	UMAL	01 August 2010
Letter of invitation to participant: Service User	2.6	14 December 2010
Letter of invitation to participant: Staff	2.6	14 December 2010
Investigator CV: Emma Kaminskiy		05 November 2010
Investigator CV: Shulamit Ramon		04 November 2010
Response to Request for Further Information		14 December 2010
Participant Information Sheet: Staff	3.0	14 December 2010
Letter from Sponsor: Anglia Ruskin University		03 November 2010
Participant Consent Form: Phase One - Research Interview	3.1	14 December 2010
Participant Consent Form: Phase Two - Recorded Meeting	3.1	14 December 2010
Interview Schedules/Topic Guides: Service User	2.2	04 November 2010
Interview Schedules/Topic Guides: Practitioner	2.0	04 November 2010
Participant Consent Form: Phase Three - Discussion Group	3.1	14 December 2010
Protocol	3	04 November 2010
Participant Information Sheet: Service User	3.0	14 December 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views

known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

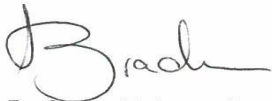
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0311/58

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



PP

Dr Steve Eckersall
Chair

Email: anna.bradnam@eoe.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Cc: Tina Moules (Sponsor Contact)
Anglia Ruskin University
Webb 109, East Road
Cambridge
CB1 1PT

Dr Belinda Lennox (NHS R&D Contact)
Cambridge and Peterborough NHS Foundation Trust
R&D Department, Box 277, Addenbrookes Hospital
Hills, Road, Cambridge, CB2 0QQ

Ms Emma Kaminskiy (Home address)
140 Thornton Road
Cambridge
CB3 0ND

Appendix VII. Example transcript and coding following a collaborative analysis session

N vivo coding framework from collaborative analysis transcript (service user 3)

SU3 coll analysis 1

Name	Sources
<input checked="" type="checkbox"/> themes which stick out or are unusual different to others	0
<input type="checkbox"/> not being informed about additive medication	1
<input type="checkbox"/> getting a second opinion	1
<input type="checkbox"/> frame of mind when nothing helping	1
<input type="checkbox"/> acknowledging social and psych factors as important, not just medical	1
<input type="checkbox"/> having a buffer or contingency plan	1
<input type="checkbox"/> information leaflets being emailed not helpful	1
<input type="checkbox"/> individualised approach	1
<input type="checkbox"/> weekly meetings with psychiatrist - unusually often	1
<input type="checkbox"/> doing own research not relying on info sheets	1
<input type="checkbox"/> has recovered well	1
<input type="checkbox"/> long term relationship buffer to SDM when ill	1
<input type="checkbox"/> typically no continuity with psychiatrist today as problem	1
<input checked="" type="checkbox"/> overarching themes from this transcript	0
<input type="checkbox"/> being under pressure to say is better	1
<input type="checkbox"/> feeling cant be honest	1
<input type="checkbox"/> superficially polite as barrier	1
<input type="checkbox"/> CPN more open dialogue	1
<input type="checkbox"/> power authority of psychiatrist	1
<input type="checkbox"/> Example of good collaboration	1
<input type="checkbox"/> SU able to be involved - savvy, informed, being well	1

being under pressure to say is better
feeling cant be honest
superficially polite as barrier
CPN more open dialogue
power authority of psychiatrist
not being informed about additive medication
getting a second opinion
frame of mind when nothing helping
acknowledging social and psych factors as important, not just medical
having a buffer or contingency plan

information leaflets being emailed not helpful
individualised approach
weekly meetings with psychiatrist - unusually often
doing own research not relying on info sheets
has recovered well

long term relationship buffer to SDM when ill
typically no continuity with psychiatrist today as problem
Coding Density

SU able to be involved - savvy, informed, being well

Example of goo

Name: TRANSCRIPT COLL ANALYSIS1

¶1:

¶12: TRANSCRIPT COLL ANALYSIS1 (47.39) [MALE/FEMALE]

¶3:

¶4: (F) = FACILITATOR.

¶5: (SR) = FEMALE CO-RESEARCHER.

¶6: (NM) = MALE CO-RESEARCHER.

¶7: (DN) = MALE NURSE.

¶8:

- (1) ¶9: (F) I think the batteries get eaten up quickly, I don't know why. Who wants to start? I don't know how best to start this? What's your overall impression of the interview maybe? Maybe that's a good place to start?
- (2) ¶10: (SR) I think it's a very good interview, in my opinion but that was partly because that was a service user...
- (3) ¶11: (F) Okay...
- (4) ¶12: (SR) which facilitates the process doesn't it? Like, she knew all the names of her medications and things, so there was no sort of beating around the bush about you know, I think I'm on so and so and you know, she was well informed about everything. So, the interview was good and it's well structured and everything, it's very easy to read but that's partly, as I say because of the...
- (5) ¶13: (F) Yeah, something about her knowing and being informed about a lot.
- (6) ¶14: (SR) Yeah and as I actually read through it, although what you said about, I actually noticed that in fact, all the markings that are made are at the beginning and then, there was less content that I was picking up on that was really important towards the end. So what perhaps you're saying is, you could have shortened the interview because most of the really interesting stuff is in the first half?
- (7) ¶15: (F) Okay, Nasar; what are your thoughts about the interview generally?
- (8) ¶16: (NM) Generally, if I can compare it to other interviews, it's all coming out with the same kind of theme you know with the same issues with the service user, them being in a position to be able to make decisions and the interviews all have the same structure you know and how they turn out.
- (9) ¶17: (F) The answers to questions or the questions themselves?
- (10)¶18: (NM) The answers to questions.
- (11)¶19: (F) Oh right, okay.
- (12)¶20: (NM) That's what I think.
- (13)¶21: (F) Oh, okay. Dominic, what are your initial thoughts about it?

	being under pressure to say is better	feeling can't be honest	
		superficially polite as barrier	
			CPN more
power authority of psychiatrist			
not being informed about additive medication			
getting a second opinion			
frame of mind when nothing helping			
acknowledging social and psych factors as important, not just medical			
having a buffer or contingency plan			
Example of good collaboration			
information leaflets being emailed not helpful			
individualised approach			
weekly meetings with psychiatrist - unusually often			
doing own research not relying on info sheets			
has recovered well			
	SU able to be involved - savvy, informed, being well		
long term relationship buffer to SDM when ill			
typically no continuity with psychiatrist today as problem			
Coding Density			

- (14)¶22: (DN) I think that there's a lot of evidence of this service user feeling that there's a collaboration between her or is it a male, I get the impression it's a female; is that right?
- (15)¶23: (F) Yes, it is a, a female.
- (16)¶24: (DN) and the consultant and CPN are at times, certainly there seems to be plenty that she's saying that supports the evidence that she gets listened to and her views lead the prescribing process, which points towards good collaboration and skills on the part of the medical professionals involved and the quality of the relationship as well seems to come out. It seems they've known each other quite a long time and I guess it makes references to sort of trust being an important factor there. I guess a really good example in that respect.
- (17)¶25: (SR) That's what I thought.
- (18)¶26: (DN) When it works.
- (19)¶27: (SR) How much of that do you think is dependent on the fact that this person, at times, has poor concentration and poor memory and is slow to make decisions, overall she's quite well informed and quite able to take on board quite a lot of information? For example, when the consultant e-mailed her, the information leaflets about the medication and everything, she was obviously able to read those and ... yeah, some people just find those... I know a lot of people find those information sheets are just too much small print aren't they?
- (20)¶28: (DN) That's right, yeah; find the right place to delve through them, that's right.
- (21)¶29: (SR) and I wonder how much that facilitates the whole process, you know, decision making but if you're actually able to engage at a level like that with your prescriber. That you're better able to have a good conversation around shared decision making or perhaps they go with the people they can relate to easier?
- (22)¶30: (F) I've just read it again, I mean for me it's because I did the interview and I have transcribed it and then I've read it, is at the end here, when they are talking about like when was it not a good meeting, you know, that question, you know, when's your negative sort of meeting and how that feeds into some of what you think she's saying there Sarah? So, right, page 13, right towards the end here; I think I wasn't able to express what I was feeling that, as I say, I got to the point when I was doubting the medication but was too scared to say anything, I think that was the main thing you know.
- (23)¶31: (SR) and also, that she feels under pressure, she feels bad every time she goes to see the consultant that she's not any better, that she feels responsible for not actually getting any better.
- (24)¶32: (F) Yeah, what her negative meeting, it's around feeling that you don't want to say that you're not better.
- (25)¶33: (DN) That's quite significant really.
- (26)¶34: (SR) I do feel that myself at times, yeah.
- (27)¶35: (DN) but it actually is a major barrier to an open discussion isn't it because if you're walking in there thinking I can't be honest, then progress is not going to be easy. So, I think that makes a really important point, you're right, it's probably something a lot of people experience, that feeling of letting the doctor down, sort of being seen as a failure because the medication hasn't worked and maybe it's nothing to do with the medication, maybe it's something else but you're not getting better, which you know, people do talk about but I think it's something that a lot of people don't mention unless they're really pushed on the subject, like in an interview like this, you know, where it focuses on those kind of questions. So, I think that's really something that I think people probably do experience but rarely say...
- (28)¶36: (F) Yeah, we never find that out.

being under pressure to say is better

feeling cant be honest

superficially polite as barrier

CPN more open dialogue

not being informed about additive medication

getting a second opinion

frame of mind when nothing helping

acknowledging social and psych factors as important, not just medical

having a buffer or contingency plan

Example of good collaboration

information leaflets being emailed not helpful

individualised approach

weekly meetings with psychiatrist - unusually often

doing own research not relying on info sheets

has recovered well

SU able to be involved - savvy, informed, being well

long term relationship buffer to SDM when ill

typically no continuity with psychiatrist today as problem

Coding Density

power authority of psychiatrist

(29)¶37: (DN) Yeah, it can be quite an obstacle sometimes because it's, you know, all superficially polite, you know.

(30)¶38: (F) Are you talking about letting the doctor down?

(31)¶39: (DN) Yeah.

(32)¶40: (SR) Yeah.

(33)¶41: (DN) Yeah.

(34)¶42: (SN) Oh yeah, when I saw my last consultant, I mean, he had aspirations for me that I couldn't fulfil, so: what do you feel? I can't live up to your expectations, medication wise this is.

(35)¶43: (DN) and I mean, you know while we're discussing this but I've sat in numerous outpatient interviews and seen the consultants saying: everything seems to be going really well and this kind of gloss and actually, I kind of know that's not the case from what I've seen and what the service has told me but there can be, if you were on your own and the consultant is coming out with this statement, if you like, that you don't agree with, it can be quite difficult to say: no, that's not the case.

(36)¶44: (F) That's not right, yeah.

(37)¶45: (NM) People usually go back to their CPN and discuss it.

(38)¶46: (F) So the person they've got the relationship with or whoever?

(39)¶47: (DN) I'll turn that off, it will shut-off in a minute.

(40)¶48: (F) That's really interesting isn't it?

(41)¶49: (SR) I agree, I think that would be something service users could relate to and have experience of but probably, as you say, don't voice it unless they've really pushed on the point.

(42)¶50: (DN) Yeah.

(43)¶51: (SR) You know, talked to them in depth.

(44)¶52: (DN) Certainly, I've seen it myself you know and obviously, if I'm there, I can act as a bit of a bridge and say: you know, maybe you've been sharing with me earlier that actually, you haven't had such a good week and that might empower somebody to say something that they might not have done before. Interesting that she also says in here, that she felt generally that it was kind of helpful to have the CPN with the consultant and that's not saying they always have a good relationship with the CPN but... and I think again, for that kind of reason, it can be helpful, depending on the relationship of course, you know to have that extra voice who perhaps can support you the same when things are not so good, if your struggling to say that yourself.

(45)¶53: (NM) I just want to try to bring up a debate on that. Would you say that means the psychiatrists authority over the service user because he's not able to voice themselves or what is?

(46)¶54: (DN) I don't know, I suppose some people might see it that way. I guess it might feel like a slightly top heavy relationship if you feel, whoever you're with, if you can't say what you feel but I guess doctors, a lot of people perceive doctors to be up here don't they, on a pedestal sort of thing?

(47)¶55: (MN) Yeah but what's happening, is because the way they're feeling, they're not saying it [can't hear next word] (10.04) or whatever.

being under pressure to say is better
 feeling cant be honest
 superficially polite as barrier
 CPN more open dialogue
 power authority of psychiatrist
 not being informed about additive medication
 getting a second opinion
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 Example of good collaboration
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- (48)¶56: (DN) Yeah, that's right, which sort of ties in to that.
- (49)¶57: (F) What do you think about that Manbassa? What are your thoughts on it?
- (50)¶58: (MN) What's my opinion?
- (51)¶59: (F) Yeah.
- (52)¶60: (MN) personally, my opinion is what I'm saying, yeah. The situation the person is in is they're circumstance, they might be feeling the doctor has an authority, they haven't voiced themselves and that's just the system, yeah. Yeah, that's what I think.
- (53)¶61: (F) That's linking in to saying about them being scared, so they're feeling because... So, you're saying that it is there, just to clarify this that there is this authority thing on or something like that?
- (54)¶62: (MN) Well, no, I'm saying the person, the service user usually, that's perceived by everyone else from these things going on, even the service user, thinks they have a level of authority and that's why the doctor because he hasn't voiced himself, you know, I hasn't answered to someone, assumed that I'm not interested, so it's like that, yeah.
- (55)¶63: (DN) I think that can be the case but the sign of a healthy relationship, when it's a bit more like this isn't it, when this patient feels able to whatever she's looking for, Re, the med's that the consultant is listening to.
- (56)¶64: (F) Yeah but in this negative example, this kind of time it didn't work well...
- (57)¶65: (DN) When she wasn't feeling so well.
- (58)¶66: (F) She wasn't being honest about; you know, the medication, yeah?
- (59)¶67: (DN) and I think that's absolutely key isn't it, when you're in there not feeling so well, a very different head space, in terms of expressing yourself when things aren't going very well and you can talk about the positives very openly.
- (60)¶68: (F) Yes and just I reflected on those 2 examples, which I think were quite contrasting examples that were given, is they were quite close in time, you know, that anyway was something that initially struck me. Obviously, we do try and keep it within a 6 month frame anyway...
- (61)¶69: (SR) I was going to say that because they were within the 6 months, I noticed that, yeah.
- (62)¶70: (F) Both were in the 6 months but considering the contrast of meetings, if you look at the different types of meeting, I just found that quite interesting.
- (63)¶71: (SR) I wasn't sure about the bit about [can't hear this drug name] (12.44), whether that was within the 6 months' timescale?
- (64)¶72: (F) Where are we [can't hear this word] (12.51).
- (65)¶73: (SR) Page 5... That's good, I went and numbered mine... the numbers are at the bottom.
- (66)¶74: (F) Sorry.
- (67)¶75: (SR) Page 5, at the bottom.
- (68)¶76: (F) 5, page 5.

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- (69)¶77: (SR) About when she was describing [can't hear this drug] (13.05), I didn't know when that actually happened.
- (70)¶78: (F) Yes, I think that was more background.
- (71)¶79: (SR) Earlier on wasn't it?
- (72)¶80: (F) Ye; probably one time I probably wasn't aware of how addictive the medication was, when I was prescribed [can't hear this drug name] (13.30), I think she was... I never asked a question about when that was, so we don't know, although I don't think it's something she's taking, so... we don't know. It was something that stood out in terms of medication being worried about her medication and in that one being addictive. Yeah; was that touching on that? What about... I thought that was a bit... that's something I've not heard in other interviews about worries about being addictive. Medication, thinking a bit more generally about how people value medication but...
- (73)¶81: (DN) I guess it raises an issue about prescribing addictive medications if she wasn't made aware, obviously well enough that, that might be the case, that raises quite an important issue in that that's important information, if it was given, it wasn't received or if it was a question about; well, the leaflet's in the box, you know and it's up to you to read it. I mean, I thought it would have been, you know, pretty important with a prescription like that to highlight the addictive nature of a drug like that and I mean, as it turns out she kind of found out herself through research, you know but perhaps ideally hope she wouldn't stop it.
- (74)¶82: (SR) Well, didn't she stop it, she stopped it suddenly and that wasn't advised. Came off it sort of cold turkey when she discovered...
- (75)¶83: (DN) After presumably having been on it for quite a while by the sound of things, yeah.
- (76)¶84: (F) That's interesting. Anything else that has really jumped out at you as being different to what either you would expect or different to other interviews that you, either last time?
- (77)¶85: (SR) I suppose the thing that jumped out to me, I think if it were me doing it, I would have gone deeper on this but it might not have been what you would have wanted. The second opinion bit really interested me because that doesn't happen so often does it?
- (78)¶86: (F) Oh, right yeah.
- (79)¶87: (SR) and I'd like to know more about the context of why that happened, you know; had the person she was seeing literally dried up with ideas? Presumably, she got the second opinion because she was referred from the consultant she was seeing, to another colleague for the second opinion. It wasn't because she was going; I am not happy with you because she seems to be quite happy doesn't she?
- (80)¶88: (F) Yeah.
- (81)¶89: (SR) and I'd like to know more about that, it's mentioned twice and where did they see the second opinion and the timescale of all that and how it... I don't know.
- (82)¶90: (F) It is mentioned again though and again it comes back to these examples because it mentioned it right at the beginning as [can't hear next 5 words] (16.31) something happened but it's about...
- (83)¶91: (SR) She had the second opinion back in July, didn't she; I was given a second opinion back in July, yes??
- (84)¶92: (F) And then if you go to page 13, I'm asking about a negative meeting and the second opinion comes out and you get a bit more understanding about that; I was sent for a second opinion, so it wasn't a request.

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- (103) §111: (SR) And to get the kind of sequence of events around this, you know, what the timings of when she saw the second opinion and everything, how long she'd been on the new drug and things. I think I would have gone there more.
- (104) §112: (F) To get a bit more context, yeah. Anything that sticks out like something that's not been mentioned?
- (105) §113: (MN) Well, I would have had quite a few questions, like on the subject of she didn't want to take her medication at all, you know, towards the end.
- (106) §114: (F) Again, going to that negative example. So saying she didn't... nothing was working or something?
- (107) §115: (MN) Because like in decision making, what was happening then, you know, what was going on when she had that frame of mind, was in that frame of mind about what happened or did anything happen sort of thing, yeah that.
- (108) §116: (F) Yes sort of what was it like to be in that... more about how experience was of being in that position.
- (109) §117: (NM) and how, if she compared it to later, how things were. How things developed or progressed, you know.
- (110) §118: (F) Yes and; are you thinking there in terms of...
- (111) §119: (MN) Frame of mind.
- (112) §120: (F) Are you thinking there as well of what's helped or what, looking back, helped or something? Are you thinking in those terms?
- (113) §121: (MN) She abused them meetings, whether she abused those meetings negatively and how positive or what she understands...
- (114) §122: (F) Yeah, I'm with you, if she's changed... I'm with you. Okay, that's really... What about you Dominic about sticking out, things that are not usual?
- (115) §123: (DN) Something that sticks out for me is the question about... towards the end when you're asking: how important do you see psychiatric medication in mental health treatment programmes and the answer is that it is one part of an overall treatment, which she makes a big point, quite an important one, the important factors that she feels that have contributed to her recovery, namely CBT and that led her to, I guess, become more insightful about the other causes of her illness and that she was able to get into voluntary work through another organisation, it very clearly says that; it aided my recovery. It's quite an important point to make there, you know, it's easy to focus on the medication but it is one part of a jigsaw, ultimately that is going to aid recovery, so it might be the necessary...
- (116) §124: (SR) That's not what we're looking at is it? We're looking at just the shared decision making.
- (117) §125: (DN) Yeah but I guess it's what she's saying though and I'm picking it out because she's making the point but you know it's... I don't know how much you want to extrapolate but the shared decision making, I tend to find that medication that makes you well enough to do these different things, so that is, if you like, the bridge to recovery, it's not just the medication. It's not just taking tablets and everything will be fine. It's, you know, she's very clearly demonstrating the process there for her, you know, it's going to be different for

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everybody. So she's saying it's not the med's, there are a lot of other factors, which I think, you know, is a significant thing.

(118) ¶126: (F) Yeah, significant point.

(119) ¶127: (DN) You're saying what's different and that's different.

(120) ¶128: (F) That's different. Can I just ask a bit about you as to why it sticks out Dominic? Is it standing out for you because of what she said or more that she was, like you've mentioned the fact, insight and sort of being able to think about the different things that's been helpful, in terms of thinking about [can't hear next 3 words] (25.14)?

(121) ¶129: (DN) I guess what's she's saying, the question is; how important and I would interpret that, as she's saying: it's not the only factor.

(122) ¶130: (F) Yeah, absolutely.

(123) ¶131: (SN) and the question is; how important do you see psychiatric medication? She is saying; it is one part of the overall recovery process, that's how I interpreted what she's saying about that.

(124) ¶132: (F) But is that unusual because you think other people don't say that? You know, I'm just trying to get an idea of why it's sticking out?

(125) ¶133: (DN) Yeah, I see what you mean. I think it depends where you are at the time. If you are acutely unwell, I guess your whole focus is going to be on the alleviation of whatever you are experiencing and medication is, like it or not, the front line treatment option. So, you know, a lot of the focus is on medication.

(126) ¶134: (F) Yes, right, very interesting.

(127) ¶135: (SR) And doesn't it require any effort at a time when you're very severely depressed, the thought of you engaging in CBT, which might involve you doing homework or exercise or any of the other things, they all require... whereas just popping a pill, bring it on, bring it on!

(128) ¶136: (DN) Oh yeah, you do need to be fairly well to do these things and of course, voluntary work, you have to be well enough to engage in that, you know, so it's yeah...

(129) ¶137: (SR) So it's a protracted proposition.

(130) ¶138: (DN) I mean, I totally accept this is about medication management and [can't hear this word] (26.42) but, you know, it is quite telling for this person, although she doesn't say, I don't see it as not important, it is but she's saying it's part of a, I guess what she's clearly describing there is a holistic approach, you know, not just medically based, there's psychological and social interventions there.

(131) ¶139: (SR) I suppose she's in a good enough place to see that as well.

(132) ¶140: (DN) Yes, absolutely.

(133) ¶141: (SR) She can look back and see that all those other things have come into play.

(134) ¶142: (DN) Yeah, that's right.

(135) ¶143: (F) That's why I'm interested in why you think it sticks out because if it's just sticking out because it resonates with you, in terms of thinking, yes it fits with my [can't hear next word] (27.34).

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- (167) ¶175: (F) I mean, we've got to focus on what this is saying and that is saying, you know, in this context.
- (168) ¶176: (DN) but the buffer thing can be both ways, that's what I'm saying.
- (169) ¶177: (F) The buffer thing can be both ways, yeah. So, in terms of what you're saying, if it was a different meeting about side effects or something like that?
- (170) ¶178: (DN) Yeah, it could be side effects or whatever. I mean, all doctors should start you off on the lowest dose there is and gradually increase but it doesn't always work like that.
- (171) ¶179: (F) At the lower end, yeah, I think maybe next time, there are other interviews, you know and there are other interviews with different meetings about different conversations about medication where some of those things are more about...
- (172) ¶180: (DN) Yeah, this is quite a positive interview really.
- (173) ¶181: (F) Yeah, exactly [Can't hear what is said here, F and SR talking over each other] (35.56).
- (174) ¶182: (SR) This is really good. This is text book stuff really, shared decision making.
- (175) ¶183: (DN) Yeah, collaborative, any consultation to go really, it's as good as you're going to get I think with her experiences with those few exceptions we've pointed out.
- (176) ¶184: (SR) Except, I suppose the chap only e-mailed her the side effect leaflets. I think that is a bit of a...
- (177) ¶185: (DN) Yeah, yeah, could have been gone over.
- (178) ¶186: (SR) Worked through it with her...
- (179) ¶187: (DN) That's right.
- (180) ¶188: (SR) Those things tend to put the fear of God into you because you read through them you know, once you've read through them, you've got every side effect they've listed haven't you?
- (181) ¶189: (DN) or you don't want to take the medication because it says; may cause death, which it says for every medication, you know.
- (182) ¶190: (SR) It's like most antidepressants, when you read those leaflets, it actually says; causes anxiety, I'm here thinking, I've got anxiety anyway and I want to take something else that causes anxiety.
- (183) ¶191: (DN) They have to put every possible reaction down, just in case somebody Sue's them.
- (184) ¶192: (NM) This goes slightly off topic, I was wondering if the psychiatrist should say; tell me everything you want done, Mark it all down; this is what we're going to do, explain at each stage why each thing is going to happen.
- (185) ¶193: (DN) That would be fantastic, yeah, that's a really good idea actually.
- (186) ¶194: (SR) That's what we're trying to do in the [can't hear this word] (37.19) programme, people are asked to select what are their priorities, in terms of benefits and side effects, what they really want. So, if you really don't want to put on weight, you can try to look for drugs that don't have that...
- (187) ¶195: (F) Yeah. Well, yes, I mean on that point I'll just reflect on the other interviews, just with the psychiatrist. I think a strong theme and I don't think any one of those interviews has not really said it about what's helpful and how maybe what's changed about it and one comment around definitely around sort of

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supporting meetings with follow up in terms of sort of writing and that side of things is sort of something that's from the fact that respect from psychiatrists help in consultations. Anything else about this transcript then because we're going a bit off and I think that's it but I think we need to keep it to what this persons saying and anything that stands out.

- (188) Q196: (SR) She's seeing a consultant on a weekly basis, which is very frequent and she was prescribing on a weekly basis, so it wasn't just the sort of block treatment, it was very much a continual appraisal of how things were going. I mean, that's very interesting isn't it? So she wasn't just being sent off with a packet of antidepressants and told to come back in 6 months?
- (189) Q197: (F) Yeah, possibly and does stand out as being not usual doesn't it?
- (190) Q198: (SR) So she thinks she wasn't having unnecessary treatment, which is always reassuring as well.
- (191) Q199: (F) Does that stand out for everyone else as not usual or something?
- (192) Q200: (DN) The frequency?
- (193) Q201: (F) Yeah.
- (194) Q202: (DN) She wasn't a private patient? You don't know that?
- (195) Q203: (F) No, oh gosh, I don't know.
- (196) Q204: (DN) because, you know, that would, you know, see them as often as you want when you're private.
- (197) Q205: (F) Oh, I don't know, just so that I understand, so is that a thing that can happen in the intake and treatment because I know she's in the intake?
- (198) Q206: (DN) Yeah, I think it's unlikely but you know, some consultants will do private work.
- (199) Q207: (F) Oh, I'm with you.
- (200) Q208: (DN) I mean, I'm certainly not suggesting that's the case but it is a possibility [can't hear next 4 words] (39.45).
- (201) Q209: (F) Let's put it in that's she's not then it is a bit unusual, yeah.
- (202) Q210: (DN) Well, I suppose, you know, if you are in hospital, it would definitely be weekly but in the community, that does seem quite [can't hear next word] (38.58).
- (203) Q211: (SR) It does seem quite good doesn't it and also, she's very hooked-in with the consultant and CPN, whereas the GP is just the prescriber, she only goes to him for the repeat prescriptions...
- (204) Q212: (F) Yeah.
- (205) Q213: (SN) That was the other thing that came over, that the GP's not in the sort of...
- (206) Q214: (DN) With the psychiatric nurse, yeah?
- (207) Q215: (SR) No, no.

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- (208) §216: (DN) I think that's quite often the case, you know, the psychiatrist is seen to be managing, unless it's antidepressants, which all GP's are kind of familiar with I guess but antipsychotics generally, you know [can't hear next 6 words] (40.39).
- (209) §217: (SR) The other thing that's interesting as well. First of all, I had to put exclamation marks where she put; a consultant ACTUALLY e-mailed me the information sheets. Actually, you know!
- (210) §218: (F) Well, I don't know how she said actually, I can't remember how she said it?
- (211) §219: (SR) Anyway, that was just a minor thing but then I suppose it's interesting that she spoke about looking on the internet, when she was researching medication, that's another thing.
- (212) §220: (F) Yes, okay.
- (213) §221: (SR) So, she's talking about... she's not only had the information sheets, also trying to see if there's other ways that she can come to a decision about them and she said nothing was really flagged up, which gave me great concern. No, wait a minute [a sentence of mumbling, due to reading by SR] (41.22 to 41.27). I think probably, yes because she goes on to describe the experience she had with [can't hear this drug name] (41.32), so she's obviously more aware about looking for things that might tell her if things are addictive or any other undesirable traits. So, I think that is quite interesting because she's not just relying on the resources that the consultants e-mailed to her.
- (214) §222: (F) Yeah.
- (215) §223: (DN) It's quite sensible isn't it, you know to do your own research?
- (216) §224: (F) Yeah. Anything Masfa? Anything else, anything else you found a bit unusual or Dominic that's a bit unusual? I think we've covered a lot.
- (217) §225: (DM) she did recover well.
- (218) §226: (SR) Oh yeah and one more thing; and I was taking it regularly. After a particular meeting, UM with second opinion, she mentioned to me that it probably it wasn't best to take the [can't hear this drug] (42.20). So was it the second opinion that mentioned that the [can't hear this drug] (42.23) wasn't best?
- (219) §227: (F) [Can't hear next 3 words] (42.28) with transcripts because, you know, I could have missed a pause here for example or something. Can I just say about this transcript, there were a number of pauses throughout most sentences and it was a generally slow pace of speech. So, it did come with... it wasn't as, you know, as flowing...
- (220) §228: (SR) as it reads?
- (221) §229: (F) It reads a lot better, the sound, you know was a bit difficult. So, in terms of trying to get meaning from that, hang on; and I was taking it regularly, then after a particular meeting with second opinion, she mentioned to me... Yeah, I think there would have been pauses in there. So it would have been; a particular meeting, and then oh and then; what shall I say something about that meeting <pause> the second opinion <pause>.
- (222) §230: (SR) This is where I'm getting a bit confused, was it the second doctor she saw about the second opinion that told her about the [can't hear this drug] (42.36); was it?
- (223) §231: (F) She mentioned....

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- (224) Q232: (SR) Is she saying: with the second opinion? So, with the doctor who gave her the second opinion?
- (225) Q233: (F) Yes, I don't know, we don't know do we.
- (226) Q234: (SR) That's what I would have liked more information about and then who prescribed what but it's so easy to say after the event isn't it? It's very difficult to think on your feet actually when you're doing those interviews because you're concentrating on so many other things like: is the tape recorder working and; is the person not getting any sort of discomfort from this interview, all the other things that are going on, you know.
- (227) Q235: (F) It is true; you are really multi-tasking; with second opinion, yeah.
- (228) Q236: (SR) So, maybe the first doctor had her on the [can't hear this drug] (44.41), it was only when she saw the other person they said it was not such a brilliant idea.
- (229) Q237: (F) Part of that one meeting where all this change happened with her medication and it all seemed to ... She seems to just about... I mean, I do think what you say is important because a lot seems to hinge on that meeting. There seems to have been a huge change, for me that stands out again about this pretty significant change and for what she's saying, this seems to hinge on this second opinion and things started to really change for her. Anyway...
- (230) Q238: (SR) I'll let you decide the answer to that one.
- (231) Q239: (F) I could just listen back to the tape, I don't think it's going to help, she doesn't specify it. Anything else?
- (232) Q240: (DN) I think the bit she states the obvious and says when she's not feeling well, you know; the meetings more difficult, you know, I think that's important. Obvious thing but, you know the process is affected by how she's feeling on the day.
- (233) Q241: (F) And that in a way the really difficult question when you're in that position.
- (234) Q242: (DN) The risk is that stuff gets missed because the patient doesn't feel able to share much and unless the doctor makes that extra effort to check that out and tries to enable the patient to be forthcoming, and then you're missing some quite crucial information that could impact on prescribing.
- (235) Q243: (F) Yeah. I'm just making assumptions but there isn't about, you know, you're prescribing at a point probably where people are not in a good place, you know, not necessarily that has happened but you would imagine wouldn't you?
- (236) Q244: (MN) It's probably about just building a relationship with the psychiatrist and, you know, people's... because it's a long treatment isn't it?
- (237) Q245: (DN) Yeah, if you've got that relationship over years, it is easier isn't it? You know, if you're not so good, hopefully that person, you know, will know because you've got that history, whereas if you've never met, they're not going to read that kind of subtlety.
- (238) Q246: (F) Yeah.
- (239) Q247: (SR) They don't know what's normal for you do they?
- (240) Q248: (DN) Exactly.

Appendix VIII. Jeffersonian transcription convention used for phase two recorded meetings

Abbreviated Jeffersonian transcription conventions.

Adapted from Atkinson and Heritage (1999), pp.160-166.

[[Simultaneous utterances
[Overlapping utterances
=	Contiguous utterances
(0.0)	Intervals between utterances
(.)	A short interval between utterance
::	Extension of sound or syllable
^	rising in intonation
___	emphasis
CAPS	Capital letters are used to indicate at utterance that is spoken much louder than the surrounding talk
(())	gesture or expression

Appendix IX. Example transcript (phase two)

UNEDITED TRANSCRIPT: ROSIE

This is a review meeting, lasting 22 minutes between Dr Kos and Rosie. No other people were present in the meeting.

2 mins: General discussion: new house and housemates, possibility of funding a course and current situation with benefits. Concerns about money.

2 mins: Rosie raises concerns about hearing voices She says *she just wants them to go away now*. Asked *how often, every day? What do they say? Extremes either good things like patronising complements or it can be the opposite negative Does mood have an effect? Yeah*

2 mins: Rosie mentions that she wants to do more exercise but that the gym is too expensive. The conversation then returns to hearing voices. R then asks *when the voices happen, how I should deal with it, should I ignore it, should I answer back?* Psychiatrist says, *Is it around when at home and no one around? R: when at work was better was more focused, P: so activity is good, so a course and learning something new is a good idea and part time jobs and routine very helpful distracting yourself or ignore.....*

6.20

1. P: Did you find actually that uh when you uh were on the amosulpride th::at you had le::ss voices than you having ye::s[
2. R: (mumbling) [h u:m
3. P: [yeah da yeah (.) but:t they probably had side effects are ::n ther[
4. R: [ye::s even on the lo::west d
5. P: [even even on the (.) fifty milligrams you had the side effects =
6. R: ye[ah
7. P: [yeah HOW do you find uh the aripriprozole do you have any problems at all and the side
8. effects with the [
9. R: [UUM I get quite sle::py [
10. P: [uh hum
11. R: um in the mornings its very difficult to g::et u::p[.
12. P: [uh hum
13. R: E:ven if I go to bed at t::en I could still (.)[wake up] at te:n or twelve e:ven (.) u::m (2) nnn
14. [uh hum]
15. R: apart from that its OKay.=
16. P: Its OK. So (.) Umm so there was also concern about we::ight gain when you went on the
17. amosulpride DO you find that you uh might have lost some weight since you are on the aripriprozole
- R: Yeah=
18. P: yes:s 9.) so it defina << ley but the voi::ces are slightly [bit worse]
19. R: [uh hum]
20. P: Do you think it is because of the medication of becasue you had a job at that ti::me and we::re 21. more busy busier [
22. R [UHHH actually I have to admi::t that I have been dri::nking alcoho::ll aswell s::oo
23. u::mm that's pro::oba::bly the thing to consider =
24. P: How m[uch

25. R: Its s::ooo difficult lik::e all the social [pressures]

26 P: [uh hum]

Time: 7.40

2 mins: Discussion about living in a shared house and peer pressure of drinking in new accommodation.

Time: 9.40

27 P: (1) A::nd do you think that uh um your house::mate might understand that you cant drink

28. alcohol or it would be difficult difficult to re::fuse=

29. R: We::ll I don't know thats the difficulty [because] he knows that I'm on table::ts so I was open

30. P: [uh hum]

31. R: about that after a couple of weeks of saying no (.). He only knows that Im on anti

32. depressants uh becasue uh theyre in my cupboard and I just thought he they might[

33. P: [Ye::S

34. R: a chance that he would see them (.) uuuhmm bu::t he's quick to label so (.) there's a lot of (.)

35. uum he also somebody to say have a drink

Time: 10.08

36. Discussion about peer pressure to drink by housemate and fear about housemates finding out
37. which medication on apart from anti depressant (stigma)

38. P: But at the moment you don't fee::l that uh they are excluding you or or they seem to be or =

39. R: I don::t kno::w I find it so::o difficult to get past my own moo::d [

40. P: [yes yes

41. R: and the voices as well

42. P: [hum um

43. R: which leads me to my next que::stion (.) would it be::e possible to try a different medication

44. at sometime

45. P: Yes I think it might be a good idea to see whether you have any (.) uh (.) I mean we switched

46. to aripipazole simply becasue of the side effects you had on on a amosulpride and uum (.) and it

47. might be worth to to try something different because even the combination of the two when you

48. were taking a very low dose of amosulpride then it seemed to work (2) because of the side

49. effects

50. R:= because of the [side effects]

51. P: [side effects exactly (.) so u::m (.) in terms of other medication I mean are

52. you happy on venlafaxine in terms of the mood do you think thats that working

53. R: Yes=

54. P: YES yes we we will not change that so really the question is whether we should change the

55. aripipazole uh the aifilofy to something different (.) in terms of uh (.) a group of medication

56. which are the same group of medication you you youve taken amosulpride and it has side effects

57. and the other ones are olanzapine uh quitayapine respiridone have you had any experience with

58. any any of these =

59. R: Unfortat::ely [

60 P: ALL OF them=

61. R: Most of them no:::ot [olanzapine] but all the rest Ive tried respiridone I find quite str[ange]

62. P: [uh hum] [huum]

63. R: quitayapine I got (.) I felt quite [fra:::ile] with it and um (2) what was the other one? =

64. P: [hummm]

65. P: Uh (1.) uh olanzapine I think olansapine what you mentioned

66. R: Olanzapine I haven't tried

67. P: Yes yes[

68. R: [Ive heard that makes you eat lo::Ads so
 69. P: Yess I mean this this can this can be a side [effect] yes
 70. R: [hummm] OKay mayb::e a low dose would be
 71. Okay=
 72. P: Yes yes yes And in terms of the uh the problem you had with the amosulpride I think it's less
 73. likely with olan::zapine (.) so youre prolactin level was quite high even on the small dose of
 74. amosulpride I hope thats much less likely on olanzapine BUT I think what we should do we
 75. should have a prolactin level tested now just to have a baseline level and probabl::y ab::out a
 76. couple of weeks later just to see whether you have any problems on olanzapine and well keep an
 77. eye on your uh on uh your eating and on your weight as well. SO IF you if you would join the gym
 78. no::w that would be a very good idea because then then uh (.) then you might be able to to kind
 79. of control the the weight gain, the weight gain unfortunatley can be side effects with the
 80. olanzapi::ne=
 81. R: Would the la::dy in the social inclusi::on (.) help me with that?
 82. P: Yes I think I think what we should do just uh (.) because um Charlie is no longer Charlie is on
 83. sick leave and you don't really need THAT kind of support that you have been receiving from her
Time 15.10.

 2 mins: Discussion about who else in the team Rosie is currently seeing. Discussion about housing contract. Discussion about alcohol, social drinking and its effects on mood

Time: 17.50

84. P: So uh HOW would you like to proceed Would you like me to uh uh to prescribe medication
 85. t oday or would you like to have some reading first uh or think about it and then um and
 86. then you can (.) see your GP and I can send the recommendation to your GP about how
 87. to change it to
 88. R: UUMM I would like it if you prescr::ibed it [today] if thats Okay
 89. P: [uh hum]
 90. P: Yes so in terms of in terms of sides effects what we discussed that if you compare to
 91. especially aripriprazole you mi::ght feel that youre appetite increased so its uuhh (.) and and
 92. weight gain might be an issue and generally also what we recommend that you have uh um a
 93. blood sugar level tested once a year (.) before you start taking the medication MAY I ask you uh
 94. (.) to have an appointment with your GP for a prolactin level tested JUSt in case to make sure
 95. that we are uh you have a normal level now if we if for ANY reason have an increased uh uh
 96. rating then its not because of the (.) ol::anzapine
 97. R: Yep yeah
 98. P: OKAY AIRIGHT, so I will I will send the fax to the GP and I will prescribe the medication and I
 99. WILL let you know how I would like you to take so you are taking uh thirty milligrams of
 100. aripriprosole is that right?
 101. R: Uh hum =
 102. P: (.) Do you take it uh in the evening or do uh
 103. R: in the evening[
 104. P: [in the evening so I WOULD like to ask you that once you start once you have the
 105. prescription or you can start the olanzapine you had a blood so if you had a blood test
 106. tomorrow you can start taking the olanzapine you DONT have to necessarily have to wait for
 107. the results (.) just I think it would be a good idea that you have a blood test first
 108. R: Okay
 109. P: So reduce the aripriprosole to twenty milligrams and take olanzapine 2.5 this would be uh day
 110. one (.) and day two (.) and the::n (.) on day three (.) please drop the aropriprosol (1) to 10
 111. milligram only and increase the olanzapi::ne [to] five milligram and then this would be day 4 (.)
 112. and day five (.)
 113. R: [yep]

114. P: You stop the aripiprosale (1)
 115. R: Okay
 116. P: But you take the olanzapine seven point five milligrams
 117. R: Okay
 118. P: And uh and I will talk to the team and also offer you an appointment in a couple of week s
 119. time to review how things are going I WOULD like you to ask to stay on the seven point five
 120. milligra::ms this especially if you found the quitapine uh a little bit making you drowsy I think
 121. you don't have to increase the dose any further
 122. R: Okay
 123. P: If you FEEL that on the seven point five you are drowsy but you absultely fine on five then
 124. just stay on five milligram [SO] so what I will do in order for you to have five milligrams and two
 125. R: [Okay]
 126. P: point five I will provide you with a prescription of two point five and five::S milligrams
 127. R: Uhhum
 128. P: so which will you the flexibility that in case if you can't tolerate the seven point five you can
 129. still reduce back to five milligrams
 130. R: OKaY
 131. P: oKAY okay.
Time: 21.06

Appendix X

Terms of reference

The terms service user and patient are used interchangeably throughout the text. This reflects the different literature which is referred to in the text and the different context and connotations the terms service user and patient encapsulate. Many other related words, such as 'consumer, client and user' are also apparent in the literature referred. These terms have not been used to allow for greater consistency and ease of reading throughout.

'Practitioner'. Again, in order to maintain consistency I adopt the wording 'practitioner'. This may reflect other terminology used in the literature including, clinician, mental health staff etc.